The prevalence and socio-cultural features of dementia among older people in rural Ghana, Kintampo

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THE PREVALENCE AND SOCIO-CULTURAL FEATURES OF DEMENTIA AMONG OLDER PEOPLE IN RURAL GHANA, KINTAMPO

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Candidate Statement and Contribution to the Work

Throughout this PhD programme, separate periods were spent in London, UK and Kintampo, Ghana. During the first 12 months of the programme in London, I took statistical research methodology courses and participated in relevant skills training. The study was independently planned and carried out with support from Supervisors, Drs Maëlenn Guerchet and Rosie Mayston, and the Kintampo Health Research Centre's research staff. Under their supervision, I refined my proposal, designed and developed a funding proposal for the study.

I spent the second 12-month period in Kintampo. Here, I co-ordinated and participated in the translation of the assessment instrument. In addition, I corrected and typed the final versions of the questionnaires in the Twi language ready for training. I worked closely with my supervisor to carry out the training of data collectors and data entry clerks, including co-ordination of the data entry with the clerks at the KHRC. I was also responsible for co-ordinating the field work, working closely with a five-member research team (4 data collectors and a Research Officer) and personally conducting some of the interviews for the quantitative component alongside them. With the Research Officer, I conducted all the in-depth interviews, completed all draft transcriptions for the qualitative component, which I then finalised under the supervision of my second supervisor upon my return to London for the third year of my PhD.

I developed the analysis plan, analysed and interpreted the findings and completed the literature review alongside the analysis processes of the study. During the final year in London, I got the opportunity to and presented the qualitative component at the annual Alzheimer's International Conference in Budapest (April, 2016). In addition, I co-authored a manuscript titled "When someone becomes old then every part of the body too becomes old: experiences of living with dementia in Kintampo, rural Ghana", which is in press with Transcultural Psychiatry for

publication. It is envisioned that further related papers on the prevalence component would be published as soon as practicable.

Abstract

Background: Dementia has been understudied in low and middle-income countries compared to the number of older people who will be at risk in these regions. So far, no population-based studies estimating the prevalence of or exploring the experiences of those living with dementia has been undertaken in Ghana, where it is evidenced that it has the fastest growing older population in the sub-Saharan region.

Aim: To investigate dementia in rural Ghana: prevalence, associated factors, experiences of persons living with dementia and their caregivers in the Kintampo Health Demographic Surveillance Site (KHDSS).

Methods: A one-phase population-based cross-sectional survey was conducted, using mixed methods. A sample of 900 persons aged 70+ years was selected from the KHDSS. The 10/66 short dementia diagnostic schedule was administered to participants in their homes alongside a structured lifestyle and risk factors questionnaire. From those with probable dementia, 10 households were selected for in-depth interviews using a case-study methodology. The experience of living with dementia from the perspective of the older person with dementia, other household members involved in the care and support were of interest, as well as decision-making processes regarding the care of affected older persons.

Results: A total of 761 participants agreed to participate and were interviewed. The response rate achieved was 84.6 %. Following the assessment, 38 people were identified with probable dementia, resulting in an overall prevalence of 5.0 % (95 % CI 3.6-6.8). The standardised prevalence for all ages was 6.6 % (95 % CI: 3.6-6.8). Dementia was associated with increasing age and more prevalent in women (6.8 %; 95 % CI 4.7-10.0) than in men (3.3 %; 95 % CI 1.9-5.5). Experiences of dementia were intertwined with other comorbidities of ageing in Kintampo. Symptoms were attributed to “normal ageing” therefore help/health seeking was

most often for physical health symptoms or issues, either by western style or traditional medicine. Care was provided mainly by female family members. Stigma was not reported in this community.

Conclusion: Dementia was prevalent in rural Kintampo, affecting more females than males. Families in Kintampo were unaware of dementia as a disease but have a coherent explanation for associated ageing health problems. They viewed the health of older people holistically and dementia was not a significant component. Hands-on care was provided mainly by women in the family and care duties appeared seamlessly absorbed within large families. There is the need to develop and provide culturally sensitive education on dementia, develop integrated health services for the care and management of dementia for older people.

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Dedication

This work is dedicated to God, Abba Father, WHO has brought me thus far. Also to my dearest daughters: Naa Amanshia, Naa Ashirifia and Naa Abeka and lastly to my wonderful grandsons, Barima and Baffour.

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List of Abbreviations

AD	Alzheimer's Disease
ADI	Alzheimer's Disease International
AGECAT	Automated Geriatric Examination for Computer Assisted Taxonomy
BPSD	Behavioural and Psychological Symptoms of Dementia
CAMDEX	Cambridge Examination for Mental Disorders in the Elderly Schedule
CERAD	Consortium of Establish a Registry for Alzheimer's disease
CSI-D	Community Screening Interview for Dementia
CST	Cognitive Stimulation Therapy
DALY	Disability Adjusted Life Years
DEMQoL	Dementia Quality of Life instrument
10/66 DRG/INDEP	10/66 Dementia Research Group/Incident Dependence
DSM-III/IV/V	Diagnostic and Statistical Manual of Mental Disorders $3^{rd}/4^{th}/5^{th}$ Editions
GDP	Gross Domestic Product
GHS	Ghana Health Service
GMS	Geriatric Mental State
GPS	Global Positioning System
GSS	Ghana Statistical Service
HAS-DDS	History and Aetiology Schedule Dementia Diagnosis and Subtype
HIC	High-Income Countries
ICD 10	International Classification of Diseases 10th Edition
IOP	Index Older Person
KHDSS	Kintampo Health Demographic Surveillance Site
KI	Key Informant
LEAP	Livelihood Empowerment against Poverty
LMIC	Low and Middle-Income Countries
MCI	Mild Cognitive Impairment
NCD	Non-Communicable Disease
NICE	National Institute for Health and Care Excellence
NINCDS-ADRDA	National Institute of Neurological and Communicative Disorders and Stroke - Alzheimer's disease and Related Disorders Association

NPI-Q	Neuropsychiatric Inventory Questionnaire
PI	Principal Investigator
PWD	People with Dementia
SRQ	Self Report Questionnaire
TB	Tuberculosis
UK	United Kingdom
WAR	World Alzheimer's Report
WHO	World Health Organization
WHO-DAS	World Health Organization – Disability Assessment Schedule
WASSCE	West African Secondary School Certificate Examination
YLD	Years Lived with Disability
ZBI	Zarit Burden Interview

CHAPTER 1

1.0 Background - Ageing

1.1 Global ageing

Current estimates of the prevalence of dementia indicated that approximately 50 million people are living with dementia worldwide (World Health Organisation, 2017a), with 2.13 million of them in sub-Saharan Africa (SSA) (Guerchet et al., 2017b). These figures were projected to reach 152 million globally (World Health Organisation, 2017a) and 7.62 million in SSA by the year 2050 (Guerchet et al., 2017b). Increased dementia prevalence is mainly driven by population ageing, with numbers of older people increasing around the world, most rapidly in low and middle income countries (LMIC) (Prince et al., 2015a). In 2017, 13% (962 million) of the estimated total population of the world comprised those aged 60 years and above. It is projected that over the next few decades, the older population will increase to 1.4 billion by 2030 and 2.1 billion in 2050 (United Nations Department of Economic and Social Affairs Population Division, 2017). Whilst some high income countries (HICs) doubled their older population over several decades (45 to 115 years), it is estimated that it will take less than 25 years for the older population of some LMICs to double (Kinsella & Phillips, 2005).

Africa is considered to have the youngest population globally. However, from 2017 to 2050, increases of the older population have been projected to occur rapidly. By 2050, 14% of the world's older population will be found in Africa (United Nations Department of Economic and Social Affairs Population Division, 2017). The population dynamics in Ghana (a nation in SSA) is no exception, with rapid increases in both the overall population and the number of people aged 60 years or above anticipated in coming decades (Mba, 2010).

Increased prevalence of non-communicable diseases (NCDs) such as heart disease, diabetes mellitus, stroke, cancer, obesity, and dementia, are associated with ageing populations. These conditions are associated with disability and extensive needs for care among older people

(Guerchet et al., 2017b; World Health Organization, 2006). According to the World Health Organization (World Health Organization, 2004), the 2004 Global Burden of Disease (GBD) study estimated that NCDs caused over 153 million Disability-Adjusted Life Years (DALYs) in SSA. NCDs alone were reported to account for 83% of Years Lived with Disability (YLDs) among the older population (60 years and above). In 2015, Alzheimer's disease and other dementias were included among the ten leading conditions listed as contributing to DALYs among older people globally (Vos et al., 2016; Prince et al., 2015a). People affected with dementia will become very ill, disabled, and dependent on families; their quality of life is impaired and life expectancy is reduced (Prince et al., 2015b) . For instance, someone living with dementia loses two thirds of one DALY for one year lived with dementia (Prince et al., 2015a). As a result, their immediate families and friends, the community, and the wider society are all inevitably affected regarding provision of either direct care or care for other health conditions (Prince et al., 2015a; World Health Organization, 2006). Although in HICs, where 23.9 % of population is aged 60 or above (Prince et al., 2015a), it has been necessary for national governments to develop policies and plans to support large numbers of older people living with NCDs, including dementia, in LMICs, no such state provision exists. This means that, in LMICs, the organisation and funding of healthcare, provision of care, and social security, are largely left to families. The extent to which this is successful, and the impacts upon families and societies is largely unknown (Mayston et al., 2017).

1.2 Ageing in Ghana

In 2010, the total population of Ghana was estimated to be 24.7 million, with a sex ratio of 95.2 males per 100 females. This number represents four times the figure (6.7 million) estimated for the entire population when the first population census was conducted in 1960. Similarly, multiple increases are observed in the older population sub-group. For instance, in 1960, the total population of older persons was 213,477. By 2010, this number had increased to

1,643,381, representing a seven-fold increase over the fifty-year period. The older population in 2015 was 1,230,134 and has been projected to increase to 1,332,721 by 2020 (Ghana Statistical Service, 2014). In Ghana, as elsewhere, the proportion of females in the population is generally higher than males; this is also the case for the older population. For instance, the proportion (56%) of older women is higher than men. In addition to this, there were more widows: nearly half (49.1%) of the aged population were widows, compared with less than a tenth (8.8%) who were widowers. This indicates a higher life expectancy for the female population (Ghana Statistical Service, 2013).

In SSA regions and across LMIC countries, low literacy is common among the older population. Currently, it is statistically evident that nearly half of all persons aged 65 or over are illiterate; only approximately 40% of older women and 60% of older men in LMICs have basic reading and writing skills (United Nations Department of Economic and Social Affairs Population Division, 2009). In Ghana, the literacy rate and educational status among the older persons are similarly low. More than a third (40%) are not literate and approximately 60% have not had any formal education. For those who have accessed formal education, there are more males than females, 30% and 13% respectively, with 1.5% of them (males) attaining higher education (Ghana Statistical Service, 2013). It should be noted that while many older people may not have accessed formal education in SSA, they are nonetheless well trained through traditional and informal systems, which prepare people to cope with and understand the rigours of life. It is possible that these non-Western educational systems may compensate for the absence of the formal education, and potentially act as a reduced risk to dementia (Guerchet et al., 2009; Guerchet et al., 2017b).

Additionally, the vast majority (93.3%) of older persons in SSA, including Ghana, regularly engage in economic activities well beyond retirement age. They could be employed or continue

to work in some capacity until they are in their 70s or even extending into the "oldest old" category - 80 years or older (Cattell, 1993), although their proportion at this stage dwindles to 3.7 percent as they reach 80+ years (Ghana Statistical Service, 2013). For example, older adults may continue to engage in economic activities including agricultural/forestry (food crop farmers), service/sales, and craft/related trade activities, among others. A majority (84.8 %) of older persons do work in any one of these three categories of livelihoods. On the other hand, owing to the low educational status amongst the elderly, very few of them were classed as having formal professional careers: professionals - 2.7%, managers - 2.2% and technicians/ associated professionals - 1.3% (Ghana Statistical Service, 2013).

It is reported that living with others, as well as engaging in and having strong social networks, can be protective against dementia (Guerchet et al., 2017b). In Ghana, older persons live with children, grandchildren, and other kin (Cattell, 1993). Such living arrangements, conditions, and types of household composition among the elderly in Ghana are similar with what may be found in several other parts of SSA. However, due to socio-cultural changes, traditionally robust social and family structures may be altering or weakening with regards to the living dynamics of the elderly (Apt, 2000). This is especially true for those who live in rural areas, compared to those in cities (Cattell, 1993; Ghana Statistical Service, 2013). Approximately 63% of the Ghanaian older population resides in rural parts of the country and 46% in urban areas (Ghana Statistical Service, 2013; Ghana Statistical Service (GSS) et al., 2015), with various forms of living arrangements. For instance, some older persons live with two or three generations – it is common to find households where parents with adult children who themselves are parents with their own families are all living together. They may be the heads, spouses of the head, the parents or parents-in-law of the head of the households they reside in, although they may not have ownership of the house. These households are comprised mainly

of members who are aged below 15 years (approximately 30 %) and those aged 15 to 59 years (ranging between 39 and 45 percent) (Ghana Statistical Service, 2013).

Households situated in both rural and urban areas of Ghana are of various types and constituents (nuclear/extended families). In rural areas, one or more clusters of households may be found within a compound, resulting in an "open" or communal type of living; this is unlike what is commonly found in most urban areas. There tend to be limited sanitation facilities and amenities in these compound houses. As a result, a sizeable proportion (22%) of the older persons living in such compound houses do not have access to toilet facilities, with 34% using public toilets (Ghana Statistical Service, 2013). This may be challenging for older persons, especially when they are frail or care dependent with a disability. In addition to communal living with families, religious affiliations are other ways in which people can network and interact socially. The majority of Ghanaians, especially older persons, are affiliated to a religion (95% of females and 91% of males). Therefore, they are likely to receive some degree of protection against dementia via the social networking and interactions they have with those with whom they share the same faith (Ghana Statistical Service, 2013).

Despite the rapidly ageing population of Ghana, the relative importance of dementia as a public health problem is not known. Among NCDs and mental health conditions, dementia ranks as a very serious condition and has one of the biggest burdens of disease among the elderly (Prince et al., 2015a). Considering the projected ageing of Ghana's population, there will be a rise in NCDs, including mental disorders and dementia, likely compounded by factors including globalisation, rapid and unplanned urbanisation, weak national health systems, and lifestyle changes, such as tobacco use, physical inactivity, and consuming unhealthy food (World Health Organisation, 2014; De Graft Aikins et al., 2012). Dementia's relative importance as a public health concern is therefore likely to increase in coming years. There is already evidence

that NCDs and mental health conditions are a major and growing health concern (Ghana Health Service (GHS), 2015). Living with two or more NCD (physical or mental) conditions (such as hypertension angina and depression, for example) (World Health Organisation, 2014) is associated with disability. According to the 2010 Population and Housing Census report, older persons have one or more type of disability (12%) more frequently than those aged below 60 years (2%). The report estimated that 13% of older people were living with a disability in rural areas compared to 15% in urban areas. The four most common causes of disability (both physical and mental) affecting older people in Ghana are: sight (29.0 %); physical functioning (18.4 %); emotional (13.4 %); and intellectual (11.0 %) (Ghana Statistical Service, 2013).

The growth in the ageing population in Ghana is outpacing the country's socioeconomic development (World Health Organisation, 2014). Meanwhile, the country does not appear to be prepared to cater to the needs of an increasing older population, particularly in regards to mental health. Ghana's GDP is US$ 1,381.41 (approximately GHS 4.4 billion). Despite the WHO's general recommendation that countries allocate at least 5 percent of their total health budget to mental health, Ghana spends as low as 3.6% of its GDP on health, with a health expenditure per capita of US$ 58.00 (Bank of Ghana, 2015). Doku et al. (2012) cited figures suggesting that Ghana allocates only 2.2% of its overall health budget to mental health care (Doku et al., 2012). This is the most likely resource pool out of which the cost of care for dementia is most likely to come. The projected health and financial burdens of dementia in the near future are of significant concern.

CHAPTER 2

2.0 Background - dementia

2.1 Dementia definition and presentation

In recognition of the contemporary use of the term, and situated within a biomedical framework, Albert et al., (2011) define dementia as: "a complex syndrome characterised by global and irreversible cognitive decline that is severe enough to undermine daily functioning such as thinking, analysing and remembering". According to Chapman (2006), dementia is not a single disorder, but rather a number of syndromes associated with varied cognitive, emotional and behavioural malfunctioning. The four main subtypes of dementia account for 90% of all dementia cases commonly identified (Abbott, 2011; Campbell, 1996). They include: Alzheimer's disease (AD), Vascular dementia (VaD), Frontotemporal dementia (FTD), and Lewy body dementia (LBD) (Campbell, 1996; Abbott, 2011). Table 1 presents a description of the underlying neuropathology, early symptoms, and the percentage of the global dementia burden represented by these four conditions. Little is known about the distribution of these sub-types in LMICs (Chandra et al., 1994).

Chertkow et al., (2013) provides a definition which highlights the social dimension of dementia. They define dementia as "a clinical syndrome of cognitive decline of the brain that is severe enough to have negative impact on social or occupational functioning" (Chertkow et al., 2013). Recognising the multiple dimensions of dementia, the World Health Organization (WHO) describes it as a chronic illness that occurs from the interplay of genetic, environmental and behavioural factors, and has severe adverse influences on social and physical activities and on the quality of life of an affected person. Capturing the long term and progressive nature of the disease, alongside its social, behavioural and emotional control dimensions, George-Carey et al. (2012) note that the deterioration in cognitive function is commonly accompanied by a decline in emotional control, social behaviour, or motivation.

People with dementia commonly experience impairments in occupational and social functioning and may present behavioural disturbances (Steinberg et al., 2003; World Health Organisation, 2012). Alzheimer's Association lists ten clusters of deficiencies of dementia or Alzheimer's as typical sympoms of the condition. They include: ***1)*** memory loss that disrupts daily life; ***2)*** challenges in planning or solving problems; ***3)*** difficulty completing familiar tasks at home, at work or at leisure; ***4)*** confusion with time or place; ***5)*** trouble understanding visual images and spatial relationships; ***6)*** new problems with words in speaking or writing; ***7)*** misplacing things and losing the ability to retrace steps; ***8)*** decreased or poor judgement; ***9)*** withdrawal from work or social activities; and ***10)*** changes in mood and personality (Alzheimer's Disease Facts and Figures 2017: 9).

Table 1. Subtypes of Dementia and Associated Characteristics

Dementia subtype	Early, characteristic symptoms	Neuropathology	Proportion of dementia cases
Alzheimer's disease (AD)	Onset is gradual. Impaired memory (difficulty remembering recent conversations, names or events), apathy and depression during early stages. Later stages include impaired communication, disorientation, confusion, poor judgement, behaviour changes, and ultimately, difficulty speaking, swallowing and walking.	Progressive accumulation of protein fragment beta amyloid outside neuron in the brain (Cortical amyloid plaques) and twisted strands of the protein tau inside neurons (neurofibrillary tangles). These changes are eventually accompanied by the damage and death of neurons.	50 -75%
Vascular dementia (VaD)	Previously known as multi-infarct or post-stroke dementia. Similar to AD, but less common as a sole cause of dementia. Unlike Alzheimer's memory less affected and mood fluctuation more prominent; impaired judgment or ability to make decisions, plan or organize; people with VaD can have physical frailty; difficulty with motor function, especially slow gait and poor balance-location, number and size of brain injuries determine whether dementia will result/how the individual's thinking and physical functioning will be affected. Stepwise onset; coexist with Alzheimer's (Mixed dementia).	Cerebrovascular disease-occurs most commonly from blood vessel blockage; Single infarcts (strokes)/ bleeding in critical regions of brain, or more diffuse multi-infarct disease.	20 -30%
Dementia with Lewy Bodies (DLB)	Symptoms common in Alzheimer's, but are more likely to have initial or early symptoms of sleep disturbances; marked fluctuation in cognitive ability; well-formed visual hallucinations; slowness, gait imbalance or other Parkinsonism (tremor and rigidity). These features, as well as early visuospatial impairment, may occur in the absence of significant memory impairment. Brain changes of DLB alone can cause dementia, but very commonly brains with DLB have coexisting Alzheimer's pathology as well as VaD, contributing to the dementia.	Cortical Lewy bodies – abnormal aggregations or clumps of protein (alpha-synuclein) in neurons developed in a part of the brain called cortex	<5%

(*Continued***)**

Cause/Subtypes of Dementia and Associated Characteristics

Dementia cause/subtype	Early, characteristic symptoms	Neuropathology	Proportion of dementia cases
Frontotemporal dementia (FTD)	Early symptoms of marked personality changes; mood changes; disinhibition; producing/comprehending language difficulties. Unlike Alzheimer's, memory is typically spared in the early stages of disease.	No single pathology – damage limited to nerve cells in the front (frontal lobe) and side regions (temporal lobes), which become markedly atrophied (shrunken); upper layers of the cortex typically become soft and spongy and have protein inclusions (usually tau protein or the transactive response DNA-binding protein).	5 -10%

Source: World Alzheimer's Disease International Report 2009 & Alzheimer's Association 2017 Alzheimer's Disease Facts & Figures

2.2. Treatment modalities

Dementia is a condition for which there is no cure. In some parts of the world, where there is infrastructure to support the management of the disease as well as support caregivers for individuals with dementia, there is evidence to suggest that diagnosis can be helpful (Boseley, 2012). However, in LMICs, where there is a lack of specialist services to address the health of older people and their cognitive health, the subject of whether or not to make a diagnosis is a topic open for debate. The search for the treatment for dementia has not been very successful. The condition is long lasting and debilitating and, as such, management and provision of care virtually become the treatment. People can live with dementia for many years if there is a timely diagnosis and the right support (Boseley, 2012). Therefore, early detection information is crucial to prepare potentially affected persons, and as well as their caregivers, and useful to manage the condition.

The US Food and Drug Administration has approved a drug, Memantine, which has been shown to regulate receptor activity affecting the neurotransmitter glutamate, which is implicated in AD (Reisberg et al., 2003). The destruction of neurons which release the neurotransmitter acetylcholine appears to be common among people with AD and some types of dementia. Cholinesterase inhibitors were developed to mitigate this. The proven pathway behind Cholinesterase is that it blocks the enzyme responsible for breaking down acetylcholine levels in the brain, thereby slowing down the destruction of the neurons which release the neurotransmitter acetylcholine (Schatzberg et al., 2003). It has been reported that the use of cholinesterase inhibitors delay the need for nursing home care by approximately 21 months for individuals with AD (Geldmacher et al., 2003). Use of cholinesterase inhibitors have also been reported to reduce behavioural symptoms (Grossberg, 2002).

While there is no available cure for dementia at the present, current studies have found that timely pharmacologic and psychosocial interventions may slow cognitive decline among people with dementia (Chapman et al., 2006). Evidence suggests that in HICs, non-pharmacological treatment approaches exist which are person-centred, and focus on identifying and meeting the unique needs of individual patients (Legere et al., 2017). Some approaches involve the creation of safe and consistent environments with moderate stimulation, others consist of the application of simple behavioural techniques and/or family counselling (Richards & Hendrie, 1999; Prince et al., 2013b).

Additionally, multicomponent interventions for caregivers have been found to be helpful. Such interventions often incude education, training, support and respite for the caregiver, designed to maintain their mood and morale and reduce strain (Prince et al., 2013b). The National Institute for Health and Care Excellence (NICE) in the UK has recommended Clinical Guideline 42 (CG42) for behavioural interventions, and this includes: integrating health and social care; understanding risk factors; prevention and early identification; diagnosis and assessment; interventions for cognitive and non-cognitive symptoms; treatment for comorbid emotional disorders, palliative care; and support and interventions for carers (National Institute for Health and Care Excellence, 2016).

Care for dementia, and other health conditions affecting older people in LMICs, are mostly addressed as part of a broader horizontal package and delivered at a primary care level. This may be based on task sharing of formal and informal providers addressing symptoms, rather than based on formal diagnoses. Families remain the core around which care and support for the aged is centred, including those suffering from dementia in most LMICs and sub-Saharan Africa. However, as traditional family systems are changing, those traditionally responsible with providing care for the aged are either too few or may be ill prepared to cope with the

distress associated with caring for an elderly relative presenting symptoms of dementia as the illness progresses.

Nevertheless, there is evidence offering potential strategies for dealing with these problems. Several studies, including the 10/66 Dementia Research Group's population-based studies conducted in settings across LMICs in Asia, Latin America and sub-Saharan Africa, have resulted in the development of guidelines for interventions for the care of older people (I-COPE). The I-COPE guide outlines components that should be considered in designing integrated care for older people at both the clinical and community levels. However, more research is needed regarding the relative importance of the different components of care, and how to effectively scale them up and give quality of life to affected persons and their carers (World Health Organisation, 2017b).

In rural Tanzania, researchers assessed the feasibility and clinical effectiveness of a psychosocial group-based intervention for dementia, the Cognitive Stimulation Therapy (CST). They found substantial improvements in cognition, anxiety and behavioural symptoms, as well as smaller improvements in quality of life measures among the 34 participants with mild/moderate dementia. The study authors have argued that CST may be a viable and culturally appropriate tool to help reduce the large treatment gap for people with dementia and their families in SSA settings (Paddick et al., 2017).

2.3 Dementia diagnosis

Memory problems are common among older people. In recent years, researchers have realised that many older people with memory complaints may in fact have mild cognitive impairment (MCI) (Alzheimer's Association, 2016). It is evidenced that 32-38% of people diagnosed with MCI may in fact be experiencing the earliest stage of dementia (Alzheimer's Association, 2016). It is important that diagnosis is carefully made for older persons with memory trouble,

and that overlap in symptoms with other conditions (e.g. depression, chronic physical illnesses) are identified and factored into the diagnostic process (Burns & Iliffe, 2009; Gleason, 2003). A clinical diagnosis of dementia involves a detailed medical and neurological examination, as well as a formal mental state examination which includes cognitive testing (Richards & Hendrie, 1999). The potential for other conditions which show dementia-like symptoms to mask as dementia itself poses significant challenge to accurate diagnosis. Cognitive testing allows the detection of cognitive impairment in different domains of memory and skills (time and space orientation, naming, verbal fluency), whilst neurological and mental state examinations informs of any potential differential diagnoses which could lead to cognitive impairment at the time of the assessment (for example, depression, previous stroke, delirium, or intoxication). Dementia may be diagnosed when there is "decline in at least two areas of cognitive function, which includes memory". There should also be "interference with social or occupational functioning"; and "the absence of an alternative explanation, such as depression, for these characteristics" (Prince et al., 2003). The main diagnostic criteria used in both clinical settings and epidemiological studies include the tenth edition of the International Classification of Disease (ICD-10) (World Health Organization, 1992), the revised third edition of the Diagnostic Statistic Manual of mental disorders (DSM-III R) (American Psychiatric Association, 1987), the fourth edition of DSM (DSM-IV) (American Psychiatric Association, 1997) and the fifth edition of the DSM (DSM-5) (American Psychiatric Association, 2013), which is most comprehensive and up-to-date critical resource to diagnose and classify mental disorders at the present.

2.4 Screening instruments

Many cognitive assessment instruments exist for screening a person who may have dementia. Usually, cognitive tests include various items assessing orientation (space and time), memory, attention, language, and praxis. A non-exhaustive list of screening instruments includes: the

Mini-Mental State Examination (MMSE) and (***-il*** for the illiterate version); the Community Screening Interview for Dementia (CSI-D); the 10 Word Delay Recall Test (10 WDRT) from the Consortium to Establish a Registry for Alzheimer's disease (CERAD); and the Geriatric Mental State (GMS), to mention a few. Several of these instruments have been validated extensively and are reliable for use in cross-cultural studies. Screening instruments can be based on cognitive testing only or may include an interview with an informant and can be applied in both clinical settings and in the population. Presented next (Table 2) are a few of these assessments which have been used extensively, both in HICs and adapted for use LMICs.

Table 2: Characteristics of key dementia screening instruments

Name	Domains tested	No. of items	Population/setting		
			Clinical	Population	Primary care
MMSE – Mini-Mental State Examination	Orientation, attention & calculation, recall, language, repetition, complex commands	11	Applicable	Applicable	Applicable
GMS-AGECAT – Geriatric Mental State – A	Cognitive screening and mental state examination	322	Applicable	Applicable	
CSI-D – Community Screening Instrument for Dementia	Attention, orientation, memory, verbal fluency, judgement, abstract thinking, change of personality, decline in cognition and function	32		Applicable	Brief version
CERAD – Consortium to Establish a Registry for Alzheimer's Disease	Verbal fluency, learning and recall	2	Applicable	Applicable	Applicable
CASI – Cognitive Abilities Screening Instrument	Attention, orientation, memory, verbal fluency, judgement, abstract thinking	25	Applicable	Applicable	Applicable
IDEA – Identification and Intervention for Dementia in Elderly Africans	Delayed recall, orientation, verbal fluency and abstract reasoning, praxis and long-term memory	6	Applicable	Applicable	Applicable

2.5 Diagnostic challenges in LMIC

Cross-cultural studies present the researcher with additional challenges in the process of diagnosing dementia. This is especially so where the diagnosis is based on a decline in cognitive function and in populations where illiteracy may be high (Hendrie, 1999). Assessment of dementia is sensitive to culture and education (Prince et al., 2003). Therefore, with low levels of education, literacy and numeracy in LMICs, people who are not cognitively impaired can screen positive for dementia (Ganguli et al., 1995; Chandra et al., 1994) because the instruments used include several cognitive items and domains of orientation and short term memory which are not relevant to all settings. Using outcomes from common standardised procedures that are not educationally or culturally sensitive make the interpretation of differences in prevalence between populations problematic. This likely contributed to the findings fromr early studies of dementia prevalence in LMICs showing surprisingly low rates of dementia (Ferri et al., 2005). However, instruments can be adapted to different cultures by including informant interviews whereby persons close to the individual with suspected dementia advise on the decline in this person's cognitive and functional abilities (Hall et al., 1993). This has proven to be as effective as cognitive testing and is not influenced by a person's educational level (Hall et al., 1993; Ritchie & Fuhrer, 1992; Jorm et al., 1991). The Community Screening Instrument for Dementia (CSI-D), for example, combines culturally sensitive cognitive testing with an informant interview to produce a predictive algorithm that has been widely validated (Prince et al., 2003; Hall et al., 1993; Hall et al., 2000).

An additional challenge faced in LMICs is the lack of specialist resources to diagnose dementia, which impedes the clinical evaluation of people suspected to have dementia during a two-stage study design. This lack of clinical diagnosis can be particularly problematic when it comes to ruling out other potential conditions which show dementia-like symptoms and pose a significant threat to making an accurate dementia diagnosis. Another challenge when

implementing a two-stage approach is to limit the attrition between the first and the second phase, which has been recorded to be high in some studies (Prince et al., 2003). Participants with probable dementia may be more likely to refuse to be interviewed, to move away or to die than those without dementia. A one-stage comprehensive diagnostic method which allows information on other psychiatric diagnoses to be gathered, similar to what is done in normal clinical practice, would reduce bias in prevalence assessments and simplify statistical analysis.

In this context, the 10/66 Dementia Research Group has developed a one-stage educationally and culturally-fair diagnostic protocol for population-based research. This was done to address some of the methodological problems encountered in some studies of dementia in LMICs which is a pre-requisite for meaningful comparisons between regions (Prince et al., 2007a). This protocol includes all possible research areas on dementia for a core minimum data set, e.g., prevalence, incidence, aetiology, etc. (Prince et al., 2007a). Each core minimum assessment comprises of dementia diagnosis and subtypes, mental disorders, physical health, anthropometry, demographics, extensive non-communicable disease risk factor questionnaires, disability/functioning, health service utilisation, care arrangements and caregiver strain (Prince et al., 2007a). The 10/66 integrated dementia diagnostic assessment relies on a fully operationalised diagnostic algorithm (Prince et al., 2008). The 10/66 dementia algorithm was validated in a multicentre study including 2885 older people across 25 centres in Latin America and the Caribbean, India, China, southeast Asia and Africa (Prince et al., 2003). The full 10/66 protocol for comprehensive one-phase surveys was then used in residents aged 65 and over living in catchment areas across ten LMICs (India, China, Nigeria, Cuba, Dominican Republic, Brazil, Venezuela, Mexico, Peru and Argentina) between 2003-2006 (Prince et al., 2007a). The dementia criterion provided by the 10/66 algorithm was compared to the DSM-IV dementia criterion: a gold standard frequently used in clinical settings by clinicians and in epidemiological surveys (Prince et al., 2008). The results suggested that the DSM-IV criterion

restricts diagnosis to more severe and indisputable cases of dementia and is more likely to miss less severe dementia cases. Typically, it does not capture milder cases of dementia in less developed settings with low dementia awareness (Llibre Rodriguez et al., 2008). The 10/66 dementia diagnosis defines a broader category that may be identifying cases beyond those defined by the DSM-IV algorithm, agreeing more with the diagnoses made by local clinicians. Beyond its use by the 10/66 Dementia Research Group studies, this protocol and dementia assessment has been recently implemented in several other countries, both HICs (Portugal, (Gonçalves-Pereira et al., 2017) and LMICs in SSA (Tanzania, (Longdon et al., 2013) and Central Africa (Guerchet et al., 2013b).

However, assessment tools continue to evolve and innovative ways are being sought to make them better and more equally and widely applicable, especially where conditions and the duration to train interviewers for accurate dementia assessment may be more limited (Stewart et al., 2016). Therefore, the 10/66 DRG developed a short dementia diagnostic schedule and algorithm from their original 10/66 dementia diagnostic assessment tool. It includes the same instruments contributing to the long 10/66 diagnostic schedule and algorithm. However, the shortened version uses output from the Euro-D scale for diagnosis instead of GMS-AGECAT output used in the long version (a more detailed discussion on the Euro_D and other components are given in Chapter 4 section 4.7.1.1, page 73). It generates information similarly to the longer version with regards to; i) dementia diagnosis ii) mental disorder (only depression) iii) physical health (Stewart et al., 2016).

2.6 Prevalence of dementia

2.6.1 Global

Accurate estimates of prevalence and incidence of dementia are essential for governments to inform future policy as well as to raise public awareness of the future societal challenges

associated with this condition. However, these figures need to be updated regularly. It has been observed that the number of people living with dementia doubles every two decades as a result of the inevitable rapid growth of the world's older population (Alzheimer's Disease International, 2009). For example, Prince et al., (2009), in their World Alzheimer's Report (WAR), estimated global numbers of people living with dementia in 2010 to be around 35.6 million. By 2030 and 2050, they estimated this figure to increase multiple-fold to 65.7 million and 115.4 million respectively, with estimated prevalence rates ranging from 2.1% for western SSA to 8.5 % for Latin America, with all other regional estimates lying between 5% and 7% (Alzheimer's Disease International, 2009).

Updating their 2009 estimates in the WAR 2015, Prince et al. (2015) reported figures 12% - 13% higher than the original number, which is mainly explained by more accurate data on demographic ageing as well as new evidence available in some regions. In 2015, 46.8 million people were living with dementia worldwide. They projected this number will reach 74.7 million by 2030 and will continue to increase, reaching 131.5 million by 2050. Of those, more than 89 million elderly people could be living with dementia in LMICs by 2050 (Prince et al., 2015a). Regional prevalence rates for all those aged 60 years and above ranged from 4.6% in Central Europe to 8.7% in North Africa and the Middle East, with all other regional estimates falling between 5.6% and 7.6%. East Asia was identified as the region having the largest number (9.8 million) of individuals living with dementia, followed by Western Europe with 7.4 million, South Asia (5.1 million) and North America (4.8 million). When looking at specific countries, the study reported that the following nations have the highest number of individuals living with dementia: China (9.5 million), USA (4.2 million), India (4.1 million), Japan (3.1 million), Brazil (1.6 million), Germany (1.6 million), Russia (1.3 million), France (1.2 million), Indonesia (1.2 million) and Italy (1.2 million) (Prince et al., 2015a).

The latest estimate provided by the WHO in 2017 reported that 50 million people currently have dementia globally, with 60% (30 million) of them living in LMICs. It is projected that by 2030, the total number of those with dementia will reach 82 million. This figure will increase further to 152 million by 2050 (World Health Organisation, 2017a). These increases of current projections through to 2050 are mainly attributed to demographic ageing, occurring faster in LMICs (Prince et al., 2015a).

2.6.2 Sub-Sahara Africa

More than half (58%) of people living with dementia reside in LMICs, including SSA. This is also where much of the increase in prevalence of dementia is expected (Prince et al., 2015a). Authors of the WAR 2015 reported that the growth of numbers is incremental, increasing by 5% (63%) by 2030 and 10% (68%) in 2050 (Prince et al., 2015a). In the 2009 WAR, prevalence estimates for the African region were estimated largely based on one good population-based study, conducted in Ibadan (Nigeria) in 1995 (Hendrie et al., 1995). A very low (2.3%) prevalence of dementia was reported in this study, as compared to the rates (4.8% in the community and 8.2% in combined nursing home and community samples) estimated for a sample in Indianapolis, USA (Hendrie et al., 1995).

Using the Nigerian study as a basis, prevalence for the African region in 2001 was estimated to be 1.6% for those aged 60 years and over, with an estimated number of people living with dementia of 0.5 million (Ferri et al., 2005). For several years, prevalence estimates continued to rely on this consensus. It is worth noting that the projected increase was 234% between 2001 and 2040, resulting in an estimated 1.6 million people living with dementia in Africa. This is projected to rise to 2.54 million in 2050 (Alzheimer's Disease International, 2009) and is driven predominantly by population ageing.

Conversely, in a systematic review to assess the information on the prevalence of dementia in Africa and to estimate the current burden, George-Carey et al., (2012) included those aged 50 years or over and reported an overall prevalence of dementia in Africa to be approximately 2.4%, which translates to 2.76 million people living with dementia in 2010. About 2.1 million of these people live in sub–Saharan Africa (George-Carey et al., 2012). Seemingly, the estimates may contradict the figures of the WAR 2009. His inclusion of "*any age-group*", instead of the "usual" 65 years and above age cohorts (a strict rule for WAR authors), for such estimates is likely to largely explain the differences in prevalence and numbers living with the disease.

Since then, the evidence-base from the SSA regions to generate prevalence estimates has increased considerably and figures are reported to be changing from what was previously stated (Guerchet et al., 2017b). In 2013, Prince et al., (2013) reported an age-standardised prevalence of 4.67% and that around 1.3 million people were living with dementia in SSA, with this number rising to 5.05 million in 2050 (Prince et al., 2013a). However, a couple of years later these figures were revised. The same authors reported an age-specific prevalence of 6.4% and an age- and sex-specific prevalaence of 7.2%. These figures were higher (4.6% and 5.4% respectively) than those previously reported in the WAR 2015. This is a reflection of new and improved evidence from sub-Sahara Africa along with better precision in estimates (Prince et al., 2015a). In 2015, it was estimated that 2.13 million people were living with dementia, which is projected to increase to 3.48 million by 2030 and 7.62 million in 2050. These figures will surge by 257% in the SSA region between 2015 and 2050, with significant growths in Central and Eastern SSA (Guerchet et al., 2017b). As a result, many more of these studies are needed, perhaps relative to the size of the 60 years and over population in these countries (SSA Central-5.21 million; SSA East-20.08 million; SSA Southern-5.36 million and SSA West-17.70 million).

These latest estimates rely on a meta-analysis including studies selected using strict criteria for inclusion (population-based studies of the prevalence of dementia, sample aged 60 years and over, diagnosis according to DSM-IV or ICD-10 or similar clinical criteria and a start of fieldwork after 01/01/1980). The exclusion of studies including other neurological/psychiatric disorders, from sample register/primary care/out of date censuses, and in which dementia was diagnosed purely based on cognitive impairment, reflected on the quality of studies considered. The studies included in the meta-analysis were conducted in: Western (6), Central (4), Eastern (1) and Southern Africa (1) (Guerchet et al., 2017b) (see details below).

In Benin, two studies were conducted in Djidja and Cotonou. In Djidja (a rural area), Guerchet et al. (2009) reported the prevalence of dementia to be 2.6 % (95 % CI: 1.1-3.8). This is similar to the rates reported in Nigeria which were obtained using a comparable screening assessment instrument (CSI-D). However, different editions of the DSM (DSM-III-R/ICD10) were used in the Nigerian study and (DSM-IV) in the Benin study (Guerchet et al., 2009). In Cotonou (an urban area), Paraiso et al., (2011), reported a prevalence rate of 3.7 % (95 % CI: 2.6-4.8). Comparatively, it was a slightly higher rate than that of rural Benin, but similar to estimates of other cities in LMIC (Paraiso et al., 2011).

Four of these studies were conducted in Nigeria, specifically in Ibadan, Anambra, Lalupon and Zaira. However, the study in Anambra is yet to be published and so is excluded from this discussion. Hendrie et al., (1995), in their study of ethnic Yorubas living in Ibadan and African Americans living in Indianapolis, reported significant differences in age-adjusted prevalence rates of dementia and found a rate of 2.3% (95 % CI: 1.17-3.41) for their Ibadan sample, which was significantly lower than the rates estimated for either sample (Ibadan estimate of 4.8%; Indianapolis estimate of 8.2%) (Hendrie et al., 1995). Yusuf et al., (2011), using two diagnostic criteria to diagnose dementia (DSM-IV and ICD-10) estimated prevalence rates in Zaira of

2.8% (95% CI: 1.0-4.58), similar to those found in Ibadan and other LMICs (Yusuf et al., 2011). For their study, conducted in a rural community in Lalupon (southwest Nigeria) using DSM-IV criteria, Ogunniyi et al., (2016) estimated the age-adjusted prevalence for persons aged 65 years and over at 2.9 % (95% CI 1.6–4.4) (Ogunniyi et al., 2016a).

In Central Africa, Guerchet and colleagues conducted six population-based studies in Central African Republic (CAR) and the Republic of Congo (ROC) among people aged 65 years and above, living in rural and urban areas between 2010-2013. Using the DSM-IV diagnostic criteria for all six studies, they estimated prevalence rates for Bangui (CAR) to be 8.1% (95% CI: 5.8-10.8), Brazzaville (ROC) to be 67 % (95% CI: 4.7-9.2) (Guerchet et al., 2010), Nola (CAR) to be 8.5% (95% CI: 6.1-11.3), Bangui (CAR) to be 6.4% (95% CI: 4.4-8.9), Gamboma (ROC) 5.7% (95% CI: 3.9-7.9) and Brazzaville (ROC) 6.6% (95% CI: 4.6-9.1) (Guerchet et al., 2013b). These rates were closer to those observed in HICs than those previously reported in LMICs.

The final two studies included in the meta-analysis were both conducted in other African regions: Tanzania (Hai) and South Africa (Muangang). In Tanzania, Longdon et al. (2013), conducted the first two-phase cross-sectional survey to estimate the prevalence of dementia of those aged 70 years and older in the rural Hai district. They estimated DSM-IV prevalence to be 6.4% (95% CI: 4.9-7.9). They also found that the prevalence rate in rural Tanzania was similar to the reported prevalence in HICs (Longdon et al., 2013). Vanderpoel and Heyns teamed up with the 10/66 Dementia Research Group (DRG) in 2012 to conduct a study for those aged 65 years and above in an older urban black community in Bloemfontein, South Africa. They reported prevalence of dementia to be 6% (Vanderpoel et al., 2013) using the 10/66 criteria.

It is worth noting that there have been varied prevalence estimates reported in different countries in the SSA regions, with consistently low estimates from Nigeria. These updated figures result from improvements in the scope and quality of available evidence and estimate prevalence more successfully and accurately and estimate prevalence between 1.6%-2.1% to 4.0%-5.5% (Prince et al., 2015a; Guerchet et al., 2017b). More and more population-based studies and reports have provided evidence on the prevalence of dementia in SSA. It is essential that even further efforts be harnessed to encourage the conduct of more quality epidemiological studies in dementia. These studies are needed to further improve the accuracy of figures and inform future dementia policy and the implementation of policy in countries in the region.

2.7 Impact of dementia

The impact of dementia regarding its disease burden, financial costs and strain on carers is huge and devastating. Dementia impacts on three interconnected levels: the person with dementia; the family and friends of the person with dementia; and the wider society (Prince et al., 2015a). This point was recognised by the WHO (2006) and Brookmeyer (2007) when they stated that dementia does not affect only individuals, but that it also has additional negative economic, social, and emotional consequences for the families and caregivers of affected persons (Brookmeyer et al., 2007; World Health Organization, 2006).The person with dementia experiences the illness itself, sometimes resulting in disability, a reduced quality of life and/or a lower life expectancy. On the next level, the effects of dementia on the family and friends of the person with dementia can be substantial, as these people are the mainstay for the person with dementia with regards to care and support. The third level, the wider society, is directly affected through costs of providing health and social care from the government and through the opportunity cost of lost productivity (Prince et al., 2015a). The economic impact of dementia, both direct (medical and social care) and indirect (unpaid caregiving by families and friends) is enormous.

The global costs of dementia increased from US$ 604 billion in 2010 to US$ 818 billion in 2015, an increase of 35.4%, representing 1.09% of global gross domestic product (GDP). The cost distribution increased proportionally in LMICs, compared to a decrease in HICs. A plausible explanation is that most of the upward adjustment of numbers of people with dementia occurred in LMICs, where the costs per capita are lower. Conversely, there was a downward adjustment in numbers of people with dementia in HICs, where per capita costs are higher (Prince et al., 2015a). Most of the costs for LMICs are attributed to informal care, while the inverse is true for HICs. In SSA, estimated costs of dementia increased from US$ 4.9 billion (2010) to US$ 6.2 billion (2015). Out of this amount, informal care constituted the greatest cost: 70.6% (US$ 4.3 billion), while direct medical care cost was moderate at 19.7% (US$ 1.2 billion), and the social sector cost was lowest at 9.7% (US$ 0.6 billion) (Guerchet et al., 2017b). The direct implication of this is that families inevitably shoulder the bulk of the cost of dementia (US$ 4.3 billion) in addition to enduring the physical, emotional and psychological toll inherent to dealing with this condition in a close relative. It is important to note that the estimation of costs of dementia in SSA are mainly based on imputation because data on resource use and costs from this region are scarce (Guerchet et al., 2017b).

Dementia is distressing for the families of affected persons, including their caregivers. A stressed caregiver is less able to cope, increasing the likelihood of neglect of the person living with dementia (O'Connor, 2011). Additionally, there is evidence that caregivers give up work, education and leisure in order to provide care. They are also may be unable to cope with or tolerate certain behavioural symptoms exhibited by persons living with dementia such as wandering, aggressiveness and agitation (Shaji et al., 2003). Consequently, caregivers and family members experience many economic, physical, emotional and psychological challenges that accompany the caregiving process for persons with terminal conditions over a prolonged time period (Patel & Prince, 2001; Shaji et al., 2003; Mayston et al., 2014). Mitigating this

impact on dementia caregivers requires support from countries' health, social and financial systems (World Health Organisation, 2017a).

2.8 Factors associated with dementia

2.8.1. Sociodemographic factors

2.8.1.1 Age and sex

Evidence from several studies and meta-analyses shows a strong effect of age and sex on dementia worldwide (Alzheimer's Disease International, 2009; World Health Organization, 2006). It was evidenced that, in 2015, the estimated prevalence exponentially doubled by 5.5 year increment in age in North America, 5.9 in Latin America, 5.7 in Asia Pacific, 6.3 in East Asia, 6.5 in West Europe, 10.6 in South Asia, 10.6 in South East Asia, and 6.9 in Australasia. For Central Europe, the Caribbean and SSA the authors had estimates for only 2015 and were 6.5, 7.2 and 7.2 year increment respectively (Alzheimer's Disease International, 2009; Prince et al., 2015a). Similarly, in a recent review of evidence coming from SSA, age was reported to be the factor most consistently associated with dementia across studies (Guerchet et al., 2017b). Over the years, and across studies conducted worldwide, sex is also reported to be significantly associated with dementia (Alzheimer's Disease International, 2009; Prince et al., 2015a; Guerchet et al., 2017b). Evidence from the SSA regions (mostly LMICs) indicates that women are approximately 2 to 8 times more likely to be at risk of dementia, compared to men at ages 65 and above, and that the additional gender-related risk increases in very old age categories (Guerchet et al., 2017b). This is likely to be largely due to women living longer than men (Kalaria et al., 2008).

2.8.1.2 Education/literacy

It has been posited that cognitive reserve accumulated from several years of schooling may be protective against dementia (Mortimer, 1988). Various authors have suggested an array of

explanations for the association between literacy and/or education and dementia. One school of thought argues that people with larger brain volume (resulting from a greater number of neurons) are more likely to continue schooling for more years than those with smaller brain volume. Others explain that cognitive reserve itself helps protect against dementia. They argue that the neural networks of people who have many years of schooling may develop higher levels of intricacies and proficiencies, which may compensate for the occurrence of dementia-related pathologies (Gilleard, 1997; Tuokko et al., 2003; Meng & D'Arcy, 2012; Brayne et al., 2010; Stern, 2012, 2009).

It is this understanding that underpins the explanatory framework for the association between level of education and the risk of dementia, where education is being extensively used as a marker for cognitive reserve (Prince et al., 2014; Valenzuela & Sachdev, 2006). Nevertheless, it worth noting that attaining high levels of education may not automatically protect one from developing neurodegenerative and vascular neuropathology. However, it may lessen the impact of dementia and/or mediate the nature of the clinical expression of cognitive decline and dementia (Guerchet et al., 2017b).

Another theory is the 'use it or lose it' hypothesis, which asserts that people must be intellectually engaged all throughout the lifespan to prevent cognitive decline. They add that those who attain a high level of education may have the thirst to continue on a scholarly path throughout their life course. Additionally, the stance of some authors is that people who have attained higher educational levels may be in a higher socio-economic bracket and may enjoy healthier and more advantaged lifestyles. This may include access to superior healthcare, for instance. This association with socio-economic status and education is referred to as the 'brain-battering' hypothesis. Proponents add that these people may be exposed to less toxins and their

brains may be protected from cerebral infarct, which is a contributor to dementia (Prince et al., 2014).

Several reviews have documented the association between dementia and education (Prince et al., 2014). Updating evidence from longitudinal studies, systematic reviews and meta-analyses, Prince et al., (2014), reported an overall protective effect of education against developing dementia later in life. The risk is reduced by about 40% (RR for high versus low education =0.58). Results were comparable to those reported in previous reviews, where other authors reported a protective effect for higher levels of education. However, most of the studies in the reviews were conducted in HICs. Only two studies were included from LMICs, and these did not report statistically significant effects (Prince et al., 2014). In some studies in SSA, no association was found between education and dementia (Guerchet et al., 2012; A. Longdon et al., 2013; Ochayi & Thacher, 2006). This may be because education in sub-Saharan African communities comprises both informal and traditional systems of instruction as opposed to the formal classroom-based teaching found in HICs. Individuals are taught to understand and withstand demands from the rigours of life by immersion in it, and not only through reading, writing and arithmetic. Under these circumstances, formal education may not be the most appropriate measure for cognitive ability (Guerchet et al., 2017b).

2.8.2 Lifestyle risk factors

Lifestyle choices, such as smoking, alcohol use, dietary habits and physical activity, have strong relationships with dementia. These lifestyles are often targets of preventive programmes aimed at improving health as well as preventing dementia. There is evidence that smoking causes a wide range of diseases, including several forms of cancer, cardiovascular diseases and diabetes (Prince et al., 2014). Stroke, for instance, increases one's risk of developing vascular dementia. In a systematic review on comparative studies about smoking, either current or

lifetime smokers were more likely than never smokers to develop dementia (Beydoun et al., 2014). The relationship of alcohol and dementia has been said to be 'J' or 'U' shaped, with both heavy drinkers and those who abstain having a higher risk (Ronksley et al., 2011). In SSA, findings on the relationship between alcohol and dementia are mixed. Gureje et al., (2006), found the relationship to have a deleterious effect, whilst Pilleron et al., (2015), found it to be protective.(Pilleron et al., 2015; Gureje et al., 2006).

Dietary habits have also been reported to have an association with dementia. Evidence from cross-sectional studies showed that compared with their counterparts with dementia, healthy older people tend to have healthier diets, rich in fruits, vegetables and fish, with limited consumption of red meat and fatty foods (Prince et al., 2014). For example, diets rich in B vitamins (B6, B9, and B12) have been associated with protective effect on cognition. Antioxidants have also been suggested to prevent neurodegeneration (Mao, 2013). Another diet associated with a reduced risk of dementia is the Mediterranean diet. It consists of a high consumption of cereals, fruits, fish, legumes, and vegetables, and has been shown to reduce cardiovascular diseases, and ultimately dementia as well (Prince et al., 2014). Accumulating evidence from studies suggests that physical activity may reduce the risk of dementia by approximatey 40%. One positive effect of physical activity is its association with reduced risk of vascular diseases, which are associated with dementia (Prince et al., 2014). Overall, the vast majority of evidence on modifiable lifestyle risk factors originates in research conducted in HICs. Research designs able to establish a causal relationship between dementia and its potential risk factors are needed in SSA.

2.8.3 Disability and needs for care

Dementia is among the top ten most burdensome and prominent conditions which contribute to chronic disability and needs for care (dependence) among older people worldwide, (Prince

et al., 2015a). Dependence on caregivers begins early in the course of the condition, increasing in intensity over time, usually until the death of the affected person (Prince et al., 2013b). The demands on caregivers for individuals with dementia exceed those of caregivers for individuals with conditions such as diabetes, cancer, ischaemic heart diseases, chronic obstructive pulmonary disease and others (Prince et al., 2015a; Liu et al., 2009). For instance, it is reported that in the USA, in comparison with people with other NCD conditions, people with dementia require more help from their caregivers: with getting in and out of bed (54% vs. 42%); dressing (40% vs. 31%); toileting (32% vs. 26%); bathing (31% vs. 23%); managing incontinence (31% vs. 16%); and feeding (31% vs. 14%) (Alzheimer's Association, 2013). Studies conducted by the 10/66 DRG in the Dominican Republic and China confirm these findings among those needing care, particularly with core activities of daily living (Liu et al., 2009; Acosta et al., 2008). In addition, the 10/66 DRG population-based surveys in LMIC also showed a very strong association of dementia with disability and dependence (Sousa et al., 2009; Sousa et al., 2010b). In the analysis of family caregivers (1,500) from the 1996 National Caregiver Survey, it was found that caring for a relative with dementia entails spending significantly more hours per week providing care in comparison with those without dementia. It was also reported that having a relative with dementia impacted more on employment complications, caregiver strain and physical health problems, among others (Ory et al., 1999).

Dementia occurs as part of a picture of multiple morbidities, manifesting in difficulties in performing tasks and activities (Prince et al., 2013b). Evidence suggests that dementia may be a key contributor to both disability and dependence among older adults. The person may live for years with the disease, which progresses in severity and reductions in quality of life (Alzheimer’s Disease International, 2009). In comparing dementia with five other non-communicable diseases (depression, stroke, ischaemic heart disease, hypertension and chronic obstructive pulmonary disease (COPD)) and six self-reported physical impairments (weakness

or loss of limb, eye sight problems, stomach or intestinal problems, arthritis or rheumatism, hearing difficulties or deafness, and skin disorders), the 10/66 DRG found that dementia was the leading independent cause of both disability and dependence (Sousa et al., 2009).

2.9 Care arrangements and social and economic effects upon households help seeking behaviour and pathway to care

Care for individuals with dementia has been extensively studied in HICs in both the informal and formal sectors. For example, Stoltz et al., (2004), in their systematic review, identified the evidence on different modes of support for family carers of cohabiting older persons. Literature indicates that women are more frequently caregivers than men (Schulz & Martire, 2004; Montgomery, 1992), and that they are predominantly children rather than spouses (Yap et al., 2005).

Care arrangements for those affected by dementia and the effects of caregiving on their families and caregivers themselves have been the subject of very few studies in LMICs, particularly in sub-Saharan Africa. So far, the 10/66 DRG's population-based studies in LMIC have been the mainstay of evidence and have provided a foundation on this area of research (Kalaria et al., 2008; Prince et al., 2012; Prince et al., 2009; Shaji et al., 2003; Uwakwe et al., 2009). Most recently, the 10/66 INDEP study focused on the social and economic effects of care at the household level, examining care dependent older people, rather than people living with dementia specifically (Mayston et al., 2014). Findings from the INDEP study are relevant to this study, particularly in light of the absence of evidence on care arrangements for dementia, coupled with the fact that dementia has been identified as the most important contributor to dependence (Mayston et al., 2014).

2.9.1 Household structure

In a study conducted by the 10/66 DRG (2004), most people with dementia lived in their own homes: households with at least three other people. In India, a minority lived in three-generation households, with one or more children under the age of 16. A high proportion of dementia sufferers, particularly in India and Nigeria, were still regarded by the caregiver as the head of household. Principal caregivers tended to be women, most frequently a spouse or a child. In India, daughters-in-law were found to be less involved. A large majority of caregivers were co-resident with the person with dementia. Where the caregiver was a co-resident, increased crowding was associated with lower caregiver strain. When the caregiver lived elsewhere, crowding was strongly and positively associated with caregiver strain (Prince, 2004). The effect of "crowding" may therefore vary according to where the primary caregiver resides in relation to the individual with dementia and the rest of the family.

2.9.2 Household economics

It is evidenced that most caregivers do not have a regular job. Shaji et al., (2003) in a qualitative study in Thrissur, South India, found family caregivers had to give up their jobs as their caring roles became more demanding. Their reported monthly income varied between US$10 and US$50. However, families were generally reluctant to report their income and these figures are likely to be an underestimate (Shaji et al., 2003). The families in the study reported financial difficulties as a result of increased medical expenses, as well as a reduction in family income.

Primary caregivers often had no regular job and could no longer supplement the family income through occasional work. Other family members were unable to take on regular work as they were needed at home to assist the primary care giver. This was common when the person with dementia needed regular attention because of wandering, restlessness, irritability or incontinence. The consequences were particularly severe for the poorest families. Family

members who applied for financial assistance from the government often never received a reply before the patient died (Shaji et al., 2003). In a situation where less than one-fifth of individuals in India and Nigeria and around half of those in China and Latin America received any kind of pension, a majority of older people nonetheless contributed to household finances after taking into account other sources of income, including rental receipts and savings (Mayston et al., 2014; Prince, 2004).

2.9.3 Caregivers' health and wellbeing

In their systematic review, Stoltz et al., (2004) reported consistent high levels of caregiver burden and distress as being the most difficult aspect for them to cope with. They reported that family carers feared social isolation from their family (Stoltz et al., 2004). There is evidence to suggest that caring for a family member with dementia increases a caregiver's risk to illness and death, and a carer experiencing "burn-out" if behavioural and psychological problems in the dementia patient are not treated (O'Connor, 2011). Sleep deprivation, linked to changes in the sleep pattern of the dementia patient, may leave carers exhausted, (Lee et al., 2007) and erratic night time activity of dementia patients, reported by 70 % of carers in a controlled pilot study in the US to test effectiveness of a new night monitoring system designed for informal caregivers to use at home (Rowe et al., 2009), were cited as the major reasons for putting loved ones in a nursing home.

Community reports have shown high rates of abuse, both of and by dementia patients, and concerns have been raised about the lack of provision of emotional care for carers (Cooper et al., 2009; Connell et al., 2004). Up to 50% of dementia carers develop psychological problems during the course of caring, especially when a patient is depressed (Brodaty & Donkin, 2009). A 2-year longitudinal study in the US also revealed that the rate of depression among dementia carers was significantly higher when compared with those caring for loved ones with other

terminal illnesses, such as cancer (Schulz et al., 2003). Findings in a study in Ireland reported about 90% of carers of dementia patients experience feelings of confinement and a feeling of being completely overwhelmed by caring (O'Shea, 2007). Another study, that assessed end-of-life care in dementia, looked at the lives of 217 family carers over a period of 12 months prior to patient death and reported that over 50% of carers spent at least 46 hours per week assisting with activities of daily living; a similar number reported feeling they were on call 24 hours a day (Schulz et al., 2003).

Similar findings were reported from studies looking into care arrangements for people with dementia in LMICs by the 10/66 DRG. There was a strong association of carer strain with the following: carer psychological illness; severity of dementia; needs for care; and time spent caring (Prince et al., 2012). Carers have also reported apparent caregiver isolation when the care recipient was incontinent (Prince, 2004). However, some positive aspects of care giving have also been reported. In a systematic review entitled "The quality of the relationship between the caregiver and care-recipient, its effect on the caregiver's and care-recipient's wellbeing", by Quinn (2009), some caregivers in HICs reported high levels of satisfaction, which ultimately reduced the caregiver burden (Quinn et al., 2009). Similarly, in LMIC settings, support received from other family members residing in the same household was reported to help caregivers cope (Prince et al., 2012; Shaji et al., 2003) and alleviate some of the burden of caring for an affected person.

2.10 Beliefs about ageing

Perceptions, understanding and practices related to ageing and older people are mediated by societal norms and cultural beliefs. Thus, the experience of ageing for older people and their families varies around the world. Sociological and anthropological theories can be helpful in

framing and supporting a deeper understanding of ageing, and indeed, dementia, in different cultural settings.

2.10.1 Intergenerational reciprocity and caregiving practices

In most societies, kinship theories support the expectation that the family group provide care for the youngest generation, supporting children through to adulthood. To a lesser or greater degree, there is an expectation that younger generations will provide support for an older family member. Principles of reciprocity can be used to explain intergenerational relationships. Reciprocity describes the non-market exchange of gifts or labour, where a return is expected (Van der Geest, 2002). For example, in China, the principle of filial piety means that parents must do their best to educate and care for their children and their children in turn assume an obligation of filial piety to repay and support their ageing parents (Hwang, 1999). Notions of reciprocity and intergenerational relationships are closely linked to and interact with other cultural norms such as gender roles. In most societies, the role of caregiving, to both older and younger family members, is perceived as women's work. For instance, in Ghana, the traditional roles of men and women are sharply divided. Women perform most of the practical activities such as cooking, washing clothes, caring for the family and managing the home. Men provide care by contributing money and performing strenuous tasks around the house. However, children, both boys and girls, perform simple tasks such as bringing food, washing bowls and running errands etc. (Van der Geest, 2002). As well as varying across cultures, practices changed and adapt over time, often in response to broader societal change. For instance, in societies where more women are entering the labour force to earn better income (Anyidoho & Ampofo, 2015), the traditional role of women as carers is contested. Help that was available to support family members in the domestic sphere has decreased due to women's increased employment in the formal sector or outside the home (Atobrah & Ampofo, 2016). There is evidence that traditional gender and caregiving roles are becoming contested in the face of

changing expectations and societal norms, for example, rapidly ageing populations, more women entering the workforce, and children staying longer in education (Mayston et al., 2017).

Currently, it is industrialised, western HIC societies which have the largest proportions of older people who require care, as well as the highest proportions of female participation in the labour market. In the UK, for every 285 people aged 65 years and over, there are 1000 working people aged 16-64 years, giving a dependency rate of 28.5% (Office for National Statistics, 2017). In these countries, older people are more likely to live alone or in town environments, which may be disabling. For instance, there may be a lack of good toilet facilities, uneven sidewalk and street pavement to prevent them from falling, and/or transportation limitations (Sixsmith & Sixsmith, 2008). This reality has prompted the development of policies to facilitate state involvement in the care of older people to supplement and support that which is provided by families. This includes both residential care and improved health services designed to meet the needs of older people. One example of this was the introduction of telecare services, where information and communication technologies (ICTs) are used to help older people to live more independently in their homes (Fisk, 2003). This was done to help improve the quality of care and support for the older people in the community (Sixsmith & Sixsmith, 2008).

In Ghana, the story is different, and the difference may be relevant to other parts of SSA and other LMIC settings. For instance, the ratio of people older than 64 to the working – age population of 20–64 years old in 2015 was 1:7.1, an increase from 1:5.8 in 1966, representing a growth of 0.43% annually (Ghana Statistical Service, 2013). Unlike in HICs, where nuclear family units are predominant, traditional extended family households are more common in Ghana, as in other SSA settings. It is a common practice in several rural areas in Ghana, particularly the middle and northern parts of the country, to have adult males marry and bring their spouse to the family compound. In such arrangements, multiple nuclear families become

integrated into one large household. A wife may prepare food for the whole household and share it amongst husband, co-wives and all the children, including grandchildren from adult children (Dalaba et al., 2016). This household structure arguably supports stronger intergenerational relationships (Mayston et al., 2017; Cattell, 1993), and has precluded the need for government involvement in the support of older people.

Nevertheless, there are some examples of the government in Ghana developing policies and plans, which either directly or indirectly support the needs of older people. However, these are quite limited. For example, the National Health Insurance Scheme (NHIS) was intended to ensure equitable access to quality health services for all its citizens (Mensah et al., 2010) and to create an avenue to defray medic bills of sick older persons (Ghana National Population Council, 2007). Nevertheless, the chronic health conditions common to older persons are not well covered in the Scheme (Hanrahan, 2018). Under the National Social Protection Strategy (NSPS) 2006, the Ghana Government implemented the Livelihood Empowerment Against Poverty (LEAP), and this provides target groups such as older people with a reliable and cost-effective cash transfer to support their basic human needs, alongside the NHIS (Debrah, 2013; Ghana National Population Council, 2007). Older people aged 70 years and above are supposed to be exempt from the premium cost of the NHIS and are eligible for free registration, and can be beneficiaries to the LEAP including their families (Mensah et al., 2010). However, the coverage is small, and older persons in very remote rural areas are yet to benefit from this. In the absence of these policies and plans, families are forced into a position of being the sole source of financial and social security for older people.

In LMIC, and particularly in SSA, it is culturally expected that most elderly people are less independent and need to receive support from their families in their daily activities. This is evidenced in situations where they live in extended family households and they are exempt or

discouraged from performing strenuous and complex tasks. Hence, the decline in functioning may be less likely to be noticed or perceived as abnormal (Cattell, 1993). It has been evidenced that families do not see these presentations as a problem. This may be because symptoms are perceived as part of normal ageing (Patel & Prince, 2001). The caregiving experience may be shaped by culturally-based views about the role of caregivers and recipients, notions of distress or burden, ideas about what constitutes 'good' and 'bad' care, family styles of interaction, and beliefs about 'normal' and 'abnormal' aging (Ivey et al., 2013; Hinton et al., 1999). Meanwhile there is evidence of cross-cultural differences in caregiving, such as health practices, gender stereotypes, help seeking behaviors, and strong communal bonds (Ivey et al., 2013; Braun & Browne, 1998; Hinton et al., 1999).

Dementia is not a normal part of ageing (World Health Organisation, 2012). Misconceptions about dementia may stem from diverse cultures and their differing belief systems. Different cultures understand of issues pertaining to disease and illness differently, and this includes varying ideas about dementia. For instance, Pollit (1994) reported that dementia was perceived to be part of normal ageing in some parts of Britain. Similarly, a study in America reported that this view was common in a multi-ethnic population (Hinton et al., 2005). Other similar beliefs were found among the Goan society in India (Patel & Prince, 2001) and in some SSA countries, including Tanzania (Mushi et al., 2014).

Nonetheless, the symptoms and features of dementia are usually recognised in LMICs (Ineichen, 2000) and the behaviour of affected persons is often characterised as "childlike." Other described symptoms are "Chinnan", incontinence, intentional misbehaviour, forgetfulness (Shaji et al., 2003; Shaji et al., 2002), not recognising relatives, and talking to or seeing imaginary people (especially those who have died). Culturally-specific names for dementia include the Kiswahili name "disease of old" – "ugonjwa wa wazee" (Henderson &

Traphagan, 2005; Mushi et al., 2014; Patel & Prince, 2001), among others. In some cases, attributes of dementia symptoms are linked to other factors, like reprisal for family or ancestral sins, stresses or unrecovered traumatic incidents in life, or witchcraft (Mushi et al., 2014; Braun & Browne, 1998; Shaji et al., 2003; Mbelesso et al., 2016; Flaskerud, 2009).

Ascribed symptoms and attributes of dementia, discussed earlier, means that many people in LMICs, as well as minority ethnic groups living in HICs, may not recognise a biomedical model for dementia (La Fontaine et al., 2007; Hinton et al., 2005). This plays an important role in informing decisions on how they seek help or deal with the issue (Adamson, 2001; Ineichen, 2000). For instance, it is reported that those whose beliefs attribute the dementia phenomenon to the spiritual or supernatural realms may seek alternative care and remedies from traditional and spiritual healers or faith-based religion (Mushi et al., 2014; Uwakwe et al., 2009; Fink, 1989) in line with their cultural beliefs and practices. Despite such evidence, literature examining knowledge in dementia is limited generally in LMICs, especially in SSA (Faure-Delage et al., 2012; Fink, 1989).

2.10.2 Beliefs about dementia, illness causation

In studies examining beliefs about illness, a distinction is made between 'lay beliefs' and 'expert knowledge (beliefs)' (Nettleton, 2006). 'Lay beliefs' about the causation of an illness may be different from 'expert knowledge'. In earlier scholarship, the former was considered unscientific, but more recently, health scientists have recognised the importance of patients and lay service-user expertise and knowledge (Bury, 1997). 'Lay beliefs' inform peoples' private views about causation of illness, health care decisions and choices about medicine but 'expert knowledge' is what advises formal discourse on health, health policy, health care provision and health care decisions. Examining people's beliefs about dementia would not only help to establish affected persons' and their families' views about the illness, including what type of

medicine to administer, but also provide a rich source of information for the formulation of plans by policy makers to help design the future care for dementia.

Fink (1989), in an anthropological study of Traditional Medicine (TM) in Ghana, notes that assigning a cause to an illness determines the type of medicine one will choose for that particular illness. If one were to assign non-biological causes or supernatural causes to an illness then surely the remedy for that illness, to that person, would lay outside the jurisdiction of biomedicine or herbal medicine. Equally, if the cause of an illness were located exclusively within the social and cultural contexts then solutions to that illness would lay within the purview of of social and cultural solutions. This, according to Fink's (1989) study of Ghanaian TM, has serious implications for establishing people's beliefs about the causation of illnesses, including dementia (Fink, 1989). Practically, this would help to determine what type of medicine to choose for the treatment of dementia. Fink (1989) asserts that any illness not attributed to natural causes is directed to traditional medicine (Fink, 1989). In his longitudinal study, which determined longer term trends in the reproduction of knowledge and practice of TM in contemporary Ghana, Tsey, suggested that psychological or mental illnesses are directed to TM for treatment (Tsey, 1997).

Another concern is that family members may hide or not report the manifestations (Ineichen, 2000) of dementia, and medical intervention will not be sought: these are serious challenges in LMIC and SSA settings. The absence of formal services in LMICa has led to a heavy reliance on informal and, in particular, on family-based care for people with dementia (Prince, 2000). There is very little evidence from LMICs on the practical, emotional and economic impacts of caring for a family member with dementia.

2.11 Stigma

Stigma has been defined as "a mark or sign of disgrace usually eliciting negative attitudes to its bearer. If attached to a person with a mental disorder (or dementia) it can lead to a negative discrimination" (Thornicroft et al., 2007). The extent of the universality of concepts of stigma and their similarities across cultures is unclear (Thornicroft et al., 2007), as is the extent to which dementia is stigmatised in LMICs. Mental health problems are commonly stigmatised around the world and often lead to efforts to conceal the illness on the part of the person living with the problem and their families. A survey of mental health care consumers by Link et al. (2001), illustrates this point. The study reported that the majority of the health care consumers stated they did attempt to conceal their disorder for fear that disclosure would precipitate unfavourable treatment towards them (Link et al., 2001).

On a personal level, any person who is conscious of his/her potential stigma marker may take certain evasive actions to avoid the perceived negative consequences of the stigma. Evidence from HIC settings suggests that stigma can stem from anybody, including professionals (Link et al., 2001). It is evidenced that both the general public and healthcare providers might stigmatize older adults with psychiatric disorders (de Mendonça et al., 2003). Many dementia symptoms are similar to those of a number of psychiatric disorders, such as depression, psychosis, delirium, etc.

Chaining of the mentally ill is commonplace in countries in SSA, especially in remote rural communities where psychiatric services are scarce (Asher et al., 2017). This suggests that responses to the mental illness of a family member are influenced by social norms regarding how best to control the mental illness, which are in turn informed by historical, cultural, and symbolic practices. Such social norms become the accepted, and even expected, practices in response to mental illness, and therefore will not evoke widespread protest, particularly at the community level.

In Ghana, political apathy towards mental health, combined with widespread stigma, hampers the progress of mental health care in the country. Traditional healers, and increasingly, pastors of Pentecostal churches, continue to deal with the greatest proportion of those with mental disorders. Whilst these figures often address the spiritual concerns of the Ghanaians who use their services, there are reports of maltreatment and human rights abuses including chaining, enforced fasting, and beatings (Commonwealth Human Rights Initiative Africa, 2008). We aimed to investigate whether or not dementia, which affects older people, attracts stigma in a community in Ghana, where age is traditionally revered (Van der Geest, 2002).

CHAPTER 3

3.0 Aims and Objectives

3.1 Problem statement and rationale

Projections of the number of people living with dementia globally, as well as in Africa, highlight the looming crisis of the dementia epidemic in the coming years. The WHO made dementia a public health priority in 2012 (World Health Organisation, 2012) and issued a call to action in 2015, enjoining all stakeholders, including countries, sectors, and organisations to address together the challenges posed by dementia (Prince et al., 2015a). Ghana, like most LMICs, faces numerous competing demands on its healthcare system, from communicable diseases such as malaria, tuberculosis (TB), HIV/AIDS, reproductive and child health, and several neglected tropical diseases (NTDs), in addition to NCDs. The Ghana Ageing Policy, which includes strategies on "improving health, nutrition and wellbeing of older persons", was launched in 2010 (Tawiah, 2011). In 2012, the government requested the WHO country office to support the nation in moving from the level of policy into practice. However, no mention was made of the mental health of older people or of dementia (World Health Organisation, 2013), indicating that these aspects of the health of older people have been absent from policymaker considerations thus far.

Yet the studies which have been conducted in SSA indicate there is a disparity between research efforts, knowledge about dementia, and the size of the older population in those regions. Population-based prevalence studies have been conducted in only six countries of SSA (Guerchet et al., 2017b). Ghana is not included among the countries in which the studies were conducted, despite having one of the largest populations of older people in the Western Africa region. Accurate estimations of prevalence are essential to establish a good understanding of the scale of problem; this is, in turn, required in order to plan health services which meet the needs of the population. Evidence from epidemiological studies suggest that a large number of

potential risk factors for dementia exist (Guerchet et al., 2017b). These include both non-modifiable and modifiable risk factors. It is important to investigate these risk factors to inform health promotion activities which could lower the risk of developing dementia in late life (Prince et al., 2014). Voices of people living with dementia and their family members in LMIC are also largely absent from the literature. Understanding how families conceptualise dementia, their approaches to care and help-seeking, and how they are treated by the community around them are essential to design health and social policies and services that are acceptable to them and meet their needs. The study described in this thesis aims to address these gaps in the evidence-base, with a view to enhancing the estimation of the scale of the problem, including its wider impacts, as well as understanding how people in rural Ghana experience dementia. We intend to bring these issues to the attention of the academic community and policymakers.

3.2 Aim, research questions and objectives

Aim

To investigate dementia in rural Ghana using quantitative and qualitative methodologies to examine prevalence, associated factors and experiences of people living with dementia and their families.

Research questions / objectives

Research questions

1. What is the prevalence of dementia?
2. What socio-demographic and care related factors are associated with dementia among older people in rural Ghana?
3. What are the experiences and understandings of living with dementia among people living with dementia and their caregivers in rural Ghana?

Objectives

i. To estimate the prevalence of dementia

ii. To use quantitative methods to investigate associations between demographic, socio-economic factors, needs for care/disability, carer strain and dementia.

iii. To use qualitative methods to explore experiences: beliefs, perceptions, and understandings of dementia among older people and their families

CHAPTER 4

4.0 Methodology

4.1 Study Design

Traditionally, there are two broad approaches to social research: quantitative and qualitative, however, some studies use a blend of these two approaches (Gilbert, 2008; Punch, 2005). Polit and Hungler (1996: 15) provide the following definitions of quantitative and qualitative research methods: "Quantitative research involves the systematic collection of numerical information, often under conditions of considerable control and the analysis of that information, while qualitative research involves the systematic collection and analysis of more subjective narrative material, using procedures in which there tends to be a minimum researcher-imposed control".

Broadly, qualitative methods are distinguishable from quantitative methods when they: "focus on interpretation rather than on quantification; and place emphasis on subjectivity rather than objectivity; flexibility in the process of conducting research; orientation toward process rather than outcome; a concern with context – regarding behaviour and situation as inextricably linked in forming experiences; and finally, an explicit recognition of the impact of research process on the research situation" (Cassel and Symon, 1994; cited in Brewerton and Millward, 2001: 12). These two approaches address different research questions and purposes. Each approach has its own strengths and limitations.

The study design is a cross-sectional survey with an embedded qualitative study. The purpose of the cross-sectional survey is to quantify the burden of dementia and explore sociodemographic and health-related factors associated with it. The function of the qualitative element (Tariq & Woodman, 2013) is to expand upon this - exploring the personal narratives and context in which dementia occurs in rural Ghana. Data from the two study components

were initially analysed separately. After a description of the study setting and overall preparatory work (recruitment and training of research team, study ethics, and development of overall sampling strategy), methodologies for the two components of the study are subsequently described, first the quantitative study, followed by the qualitative study. Results for each study component are presented in Chapter 5 (quantitative) and Chapter 6 (qualitative). Overall study findings, the relationship between quantitative and qualitative results, and insights arising from carrying out these two components alongside one another are discussed in Chapter 7.

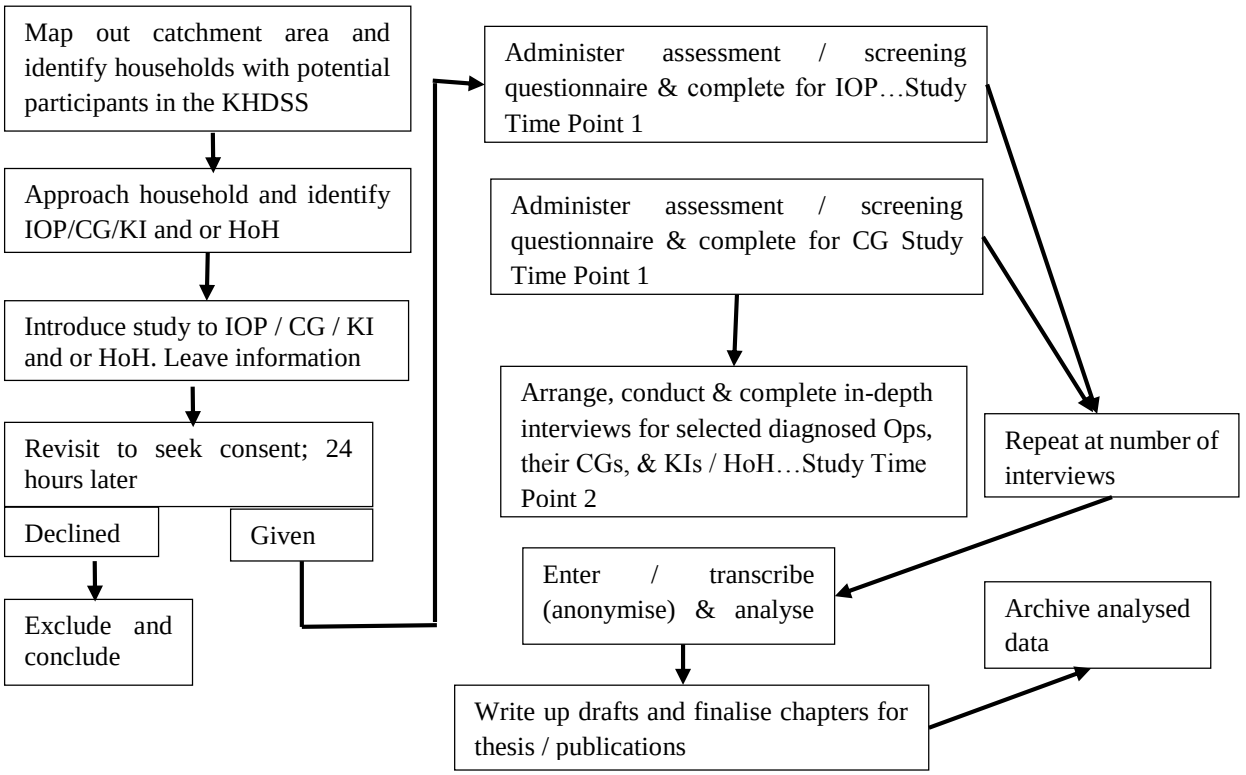

Figure 1: Overall strategy of the study.

Reflexivity

Fontana (2004) posits that reflexivity is one of the pillars of 'critical' qualitative research and relates to the amount of effect the researcher brings to bear on the findings, either intentionally

or unintentionally (Jootun et al., 2009). Additionally, it is the channel which enhances the understanding of the phenomenon being studied and the researcher's role (Jootun et al., 2009). Scholars such as Mauthner and Doucet (2003), Archer (2004), Nicholls (2009), and Carroll (2009) note that reflexivity helps the researcher to closely examine their own influence on the research process. Thus, reflexivity helps the researcher to interrogate his or her role (self-reflection) throughout the research process. This critical self-reflection includes such things as researcher's influence on the study and social positioning such as class, gender, race, ethnicity and kinship. A reflexive approach also allows for close examination of chosen methods for the research (Fonow & Cook, 2005). Furthermore, reflexivity is an ongoing process that helps bring attention to the researcher's emotions, biases and assumptions about the research (Berger, 2015) and enables the researcher to be accountable for the analysis and interpretation s/he makes of the research data (Deutsch, 2004).

Undertaking this study, including the writing up of the thesis, has been a journey of "learning" and discovery for me. It has always been my wish to see people enjoy good health (physically, mentally and socially) rather than ill health. However, I have come to the realisation that, as human beings, becoming ill from diseases is inevitable. More so for older persons, who, due to ageing, are prone to several diseases, making them frail, vulnerable and in need of much care. As I wondered how to contribute to bringing wellness and care to older persons, I felt a stirring within me to obey God's call by boldly diving into the swirling ocean of societal problems and helping those who seem beyond help. No matter how this would enfold, I have embarked on this journey to research into other peoples 'disordered' lives, brought on by debilitating diseases such as neuropsychiatric disorders; for I am persuaded that being mentally healthy is key to attaining good health in old age. As I reflect on my positionality in this research, I identify with what has been said; that the social processes I studied were not separate from me as a researcher and hence cannot escape the social world to study it (Hammersley & Atkinson,

2007). For this purpose, I draw on the terms "insider" and "outsider" to refer to my positionality as someone who might have more or less impacted the study through my ethnicity, gender, profession, experiences, values or inexperience.

Although positionality might be expected to have a differential effect upon quantitative and qualitative data, it is important to consider the impact of the researcher's identity and position in the context of both methodologies. The design of my PhD study emerged from my education in the Western scientific paradigm. As such, my starting point was the biomedical construct of dementia and the investigation of its prevalence and impact in Ghana. Although my qualitative work was more exploratory, I started from a position of: a) believing in the objective reality of dementia as a biomedical disease; b) wanting to understand how this objective reality was mediated by the social reality, understandings, beliefs and experiences of people living in rural Ghana. My approach was not *etic* to rural Ghana but rather started from an *emic* perspective and aimed to integrate an *etic* element, using the nested qualitative study. This approach is consistent with findings from others work which suggest that although the existence of broad syndromes of mental disorder may be universal to being human, these are expressed differently with patterns and prominence of symptoms varying across different cultural settings (Haroz et al., 2017; Patel, 1995; Patel et al., 1997). In this way, my study was framed by positivist notions of truth, whilst allowing space for exploration of the social construction of the reality of living with dementia in Ghana. Although the two datasets were analysed separately, I then drew results from the two together, to understand how they relate or do not relate to one another.

My role in the field took on two key roles- interviewer, undertaking all qualitative interviews and some quantitative interviews and team leader of researchers who were undertaking the majority of quantitative interviews. My behaviour and overall approach in relation to study participants was similar in terms of the type of data being collected or my role in the encounter (interviewer/supervisor). In the context of the quantitative research and data collection, in

addition to the influence my positionality had upon study design (as described above), the structure of the team and nature of data collection in relation to expectations, beliefs, understandings and experiences of participants, will inevitably have influenced the shape of the resulting data. The location of the research in the Kintampo DSS is important here. Participants were familiar with both the process of research (the nature of participation, consent etc.) as well as knowing members of the research team. This familiarity provided a good foundation for the work and for my relationship with the community, meaning that both were potentially more acceptable and normalised than they would potentially be in other areas of rural Ghana. The issue of social desirability: of participants 'performing well' in front of an educated, insider/outsider researcher and therefore not wishing to report socially undesirable characteristics cannot be ruled out but my integration into established research infrastructure and team reduced this risk as much as possible.

As an insider/outsider, my aim was to be honest and open about my position as a researcher (potential outsider) whilst putting participants at their ease- sharing the same lingua franca through my ethnicity (Twi), it conveyed a connection with the participants and avoided myself being viewed as a disconnected ethnic. I understood the language, including non-verbal cues, and, using the Twi language as a medium of communication. This perhaps was most impactful in the context of the qualitative work, where research concepts were presented to them directly without a translator, eliciting a natural flow of their narrations. Participants were more open and candid about certain issues. Hence, any margin of error in misunderstanding the meanings or interpretations of their feedback was eliminated, putting their responses, perspectives and concepts, directly in context. This is especially so when it was critical that, for medical issues, the interviewees understood the concepts directly in their own language. Similarly, I presented myself as an older and matured woman to counter the effect of perceived gender dynamics. Within traditional settings, older women are considered knowledgeable and accorded a higher

level of respect in society. Knowing this, I took the opportunity to get them to trust me as an 'equal' (balancing power), giving me the leverage to buoy up their feelings and to narrate their stories without hesitation. This position also enabled me to ask pertinent and sensitive questions, which would have been more difficult for a relatively younger person.

Though I went into the interview with an open mind, being an "insider" with regards to shared ethnicity, including in-depth knowledge of customs and codes, I might have omitted raising provocative or taboo questions in that position. In addition, I believe as an "insider", I may have left some information to go unexplained because, to the participants, I was one of them and would possess more or better knowledge and therefore understand nuances. Not only this but, I may have assumed to know or understand certain issues the participants relayed and inadvertently not asked "pointless" questions an "outsider" might have asked, that could have added depth or a different perspective to the narratives. However, it is my belief that reporting verbatim and having a consensus of expert opinions informed a more accurate picture of the information collected.

In another respect, however, I perceived myself as an "outsider". It was my first time interacting with participants in this setting. Nonetheless, as I was granted permission to interview participants by the KHRC, as well as being accompanied by their high-ranking staff, the participants often regarded me as "an insider". They welcomed me warmly into their homes, treating me as though I was a member of their family and invited me to partake in their evening meal. Since I was interviewing, I politely opted to pack mine to eat after "work"; which was the politest refusal in the context of rural life based on my experience with rural norms and values. My posture of immersion in their life, and the flexibility in engaging them as they narrated their story, allowed extended interviews when the need arose. These actions motivated them, aided confidentiality and put them at ease to share their stories. Nevertheless, my lack of first-hand knowledge and personal (relational/non-relational) experience with care for the older

person affected with dementia was clear to me. For instance, during my childhood, I witnessed care for older persons but was never privy to any discussions in relation to care provided for older persons, including my own grandmother. Although my research respondents were involved with, and more experienced in, the care of an older person living with dementia, their perception of me as an "insider" may have attenuated their articulation or explanation of some information, which may otherwise have been explained to a typical "outsider".

I was constantly aware that my positionality was not fixed and may change over time. There were instances during fieldwork where I was initially viewed as an "outsider" but as time progressed and I became a familiar face in the communities, interviewees gradually perceived me as an "insider". A case in point was when an elderly Moslem man would only talk with my male Research Officer (RO) during the very early part of the assessments of participants for the quantitative component. However, the converse was true for another elderly Moslem man who saw me as the "older woman" usually accompanied by a younger male and interacting with older persons in the community. He indicated his preference for, and insisted on, talking with me instead of the younger male RO and became friendlier, less reserved and forthcoming with information during the interviewing.

Epistemologically, I decided not to make a value-free outcome of this study. This is because the way I frame my analysis and discussion of the data, regarding the qualitative component, in relation to the experiences of living with dementia, are influenced by my identities; my fresh experience in a public health researcher in a neurogenerative disease role, one with a passion to see older people enjoy "good" health, a voice for the voiceless, and my newness in public health research ("young researcher"). Also, my analyses are influenced by my lived rural experiences as a Ghanaian as well as my "second-hand" knowledge of research processes and the phenomenon being studied. These identities and experiences frame my values. In relative terms, because the prevalence of dementia and care arrangements for the diagnosed are central

to this research, I tried to ensure that the end product of this research is epistemologically viable.

4.2. Research setting

This study was carried out in the Kintampo Health Demographic Surveillance Site (KHDSS) in the Brong Ahafo Region (BAR) of Ghana. The Brong Ahafo Region lies within the Forest Transitional Zone (middle belt) of the country and covers a surface area of 39,557 square kilometres. It is the second largest region in the country with a total population of 2,310,983, (Ghana Statistical Service, 2005). The Region has nineteen districts, two (Kintampo North and Kintampo South) of which constitute the KHDSS administratively (Figure 1). Most people in this setting speak or understand the Twi language as a second language. In terms of ethnicity, the largest groups are Akan (25%), Dagarti, Frafra, Kusasi (together comprise 17%), Gonja, Dagomba and Mamprusi (together comprise 16%), Mo (13%), Konkomba and Basare (about 11%). In Kintampo North Municipality, a combined Mos and Akans comprise 35% and Gonjas, Dagombas and Mamprusis comprise a further 20%, whereas in the Kintampo South the Akans are the single largest (36%) indigenous ethnic group. Approximately, 3% are adherents of Traditional religion or spiritualists and some 8% profess no religion. Muslims comprise a larger percentage of the population in the Kintampo North Municipality compared to those in the Kintampo South (30.7% vs. 20.6%). However, in both districts Christians form the majority, 46. % for Kintampo North Municipality and 60% for Kintampo South.

The main economic activities within the districts are in the agriculture and service sectors. The majority of the working class are farmers and may combine farming with other activities and/or the sale of agricultural products. Farming is largely driven by the two predominant vegetation types: semi-deciduous forest and guinea savannah. The first vegetation type, the moist semi-deciduous forest zone, is conducive for producing cash crops, such as timber, cocoa and

cashew. The second type, guinea savannah, is conducive for the production of food crops, such as maize, cassava, plantain, yam, cocoyam, rice and tomatoes. The towns in the guinea savannah zone, including Kintampo, are known for their high production of yam. Small merchandising and dressmaking form the bulk of service sector workers. A few workers are in government employment, mainly as civil servants or teachers. Most people find it necessary to engage in farming in addition to their main occupation and carry out agricultural activities at the weekend. Kintampo has a weekly market with people coming from all of the sub-districts to trade in yams, maize, and charcoal. Seasonally, fruits such as mangoes and watermelon are also traded. There are two main rainy seasons: the major rainy season is from March to June, and the minor rainy season is from July to November. Mostly, farming activities within these two districts, Kintampo North and South, correspond with the two rainy seasons. The dry season begins in the month of December and ends in February.

The KHDSS covers an area of 7,162 square kilometres, 18.1 % of the total land area of the region. These districts are mainly rural and are divided into twelve sub-districts, seven; Busuama, Dawadawa, Gulumpe, Kadelso, Kintampo, Kunsu and New Longoro in the Kintampo North Municipality and five; Amoma, Anyima, Apesika, Jema and Mansie in Kintampo South District. The districts are large comprise a total of 158 villages. These villages have significant differences in terms of locations and distances from their district capitals i.e. Kintampo and Jema. In 2012, the districts had a combined resident population of approximately 152,000 (Owusu-Agyei et al., 2012) (Table 1). Infrastructure in the districts is generally poor: few communities have access to electricity and few can be reached by tarmac roads.

The health infrastructure in the district includes two hospitals, six health centres, two rural clinics and 40 Community-based Health Planning and Services (CHPS) compounds. The two district hospitals are located in the district capitals of both Kintampo North and South

(Kintampo and Jema). They are manned by general practitioners who provide curative, emergency and surgical services. These hospitals also serve as referral centres for both the health centres and the CHPS compounds. In addition, the health facilities provide routine preventive antenatal, post-natal and child health (including immunisation) services, family planning and treatment for sexually transmitted diseases (STDs). They also run weekly mobile child health services in communities within their catchment areas. They are supervised by the District Health Management Team (DHMT) through scheduled and unscheduled visits. There are four medical officers, nine medical assistants and a number of trained nurses, nurse assistants and community health officers (CHOs). In the private sector, there are two private clinics and two maternity homes. There are several traditional spiritual healers and drug stores where over the-counter-drugs are available as well as a pharmacy at the district capital of the Kintampo North District.

It is common practice in several rural areas in Ghana, especially in the middle and northern parts of the country, to have adult males marry and bring their spouse to the compound. In such arrangements, multiple nuclear families become integrated in one large household with several individuals. A wife may prepare food for the whole household that would be shared amongst husband, co-wives and all the children, including grandchildren from adult children. The resident members of every compound are enumerated at a household level and their dates of birth ascertained from birth certificates, written records and local events calendars.

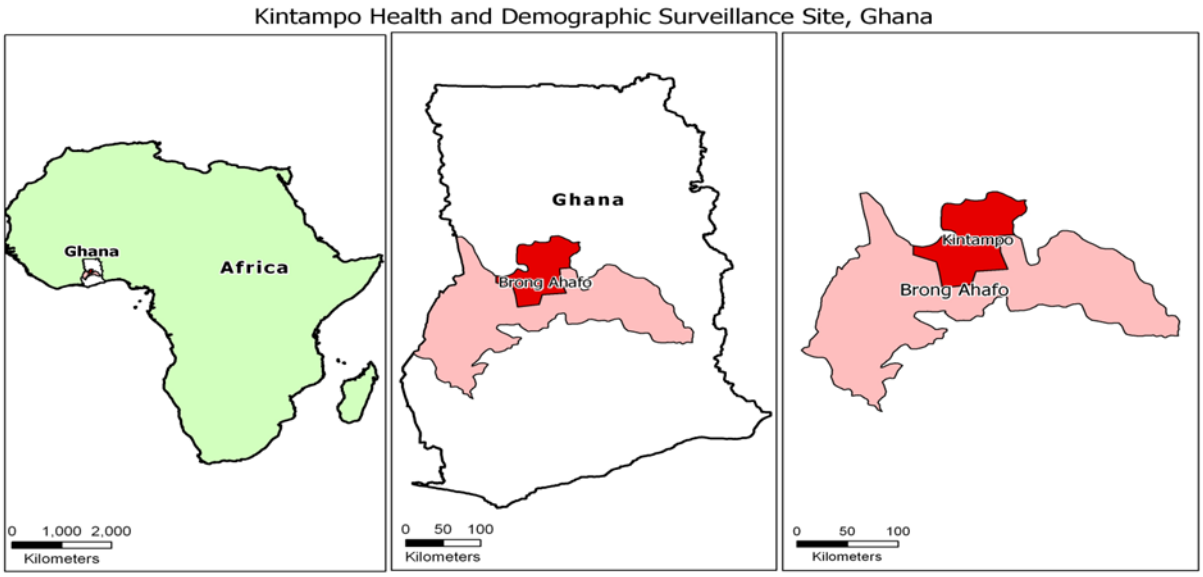

Figure 2: Map showing location of Kintampo

4.2.1. Rationale for choosing the KHDSS

The KHDSS is one of three health demographic surveillance sites situated in three strategic parts of the country: the northern zone – Navrongo, the middle zone – Kintampo; and the southern zone - Dodowa. The KHDSS served as a platform to do the baseline survey in the communities covered in the Demographic Surveillance System (DSS). The KHDSS is situated within the Kintampo Health Research Centre (KHRC) and located in Kintampo, about 600 km from Accra; the national capital. The KHDSS was established in the 1990s to monitor health and demographic dynamics and also serves as a platform for conducting health research (Owusu-Agyei et al., 2012). It has multidisciplinary technical staff totally over 500 comprising of various cadres of researchers, social scientists, laboratory technicians, data management and financial/accounting professionals. It is one of the largest health and demographic surveillance sites in SSA with one of the largest study populations (http://www.kintampo-hrc.org). Surveillance in the KHDSS is achieved through a network of village-based field workers and yearly visits to indexed individuals, households and communities (Kintampo Health Research Centre, Unpublished). The KHRC has up-to-date lists of the whole population resident in the

Municipality that was made available to the principal investigator (PI) to generate the required sample of older age bands in the population of current study.

All of the compounds in the KHDSS study area are geo-referenced with the Global Positioning System (GPS) and have been systematically allocated address codes on its database. These address codes are in turn, painted on the compounds, for easy identification of households for future research. A household, as defined by the KHDSS and used for the purposes of this study, is, "people who live together and eat from the same pot". A compound generally consists of either one family or several families of an average size between two and five, or of more nuclear/generational families within clusters of households, which may consist of two to ten roomed wings per cluster. Sometimes, a nuclear family consists of a man with several wives (two or more) and children by the individual wives.

The field workers of KHRC update the surveillance data on target populations yearly. Updates are scheduled for each household, beginning each cycle from January through to December, and account for any new households that emerge since the previous visit. Information gathered during these regular visits is used to update the records held on computerised databases at the Centre. The information held on the databases includes identifiable households, the household's socio-demographic data, data on nutrition and anthropometric status, immunisation records, morbidity and mortality events, pregnancy and pregnancy outcome events, and use of health services. The surveillance data serves as the cornerstone for all research activities in the KHRC, including the potential for evaluating the impact of intervention programmes implemented in the study area. It is this up-to-date list of the whole population resident within the KHDSS that was made available to the PI to generate the required sample of older age bands in the population of current study. Details of the composition of the KHDSS population are in Table 3.

Table 3: Population distribution: district, sex, age, Kintampo, 2015

Distribution characteristics	Total	Percentage
KHDSS districts		
Kintampo North Municipality	89, 244	59.1
Kintampo South	62, 654	40.9
Total	**151, 898**	**100.0**
Sex		
Male	74, 253	49.0
Female	77, 645	51.0
Total	**151, 898**	**100.0**
Age group in years		
0 – 59	142, 145	93.6
60 – 69	5, 531	3.6
70 +	4, 222	2.8
Total	**151, 898**	**100.0**

The focus of research of the KHRC is mainly on women of reproductive age and children less than five years of age. These include studies on malaria, maternal and child health, reproductive health, and a few areas of mental health: depression, psychosis and suicide. The research area (Kintampo North and Kintampo South) has been used for research for a number of years, although, it has not been used for research on dementia and the age group sampled for this study has never been researched in this study area. While the KHDSS collects demographic information from this age group, the Centre has never used them for as research subjects.

4.2.2. Ethical considerations

Ethical approval was sought and obtained from King's College London Ethical Committee (REC) within the Psychiatry, Nursing & Midwifery Research Ethics Subcommittee (PNM), with a reference number, PNM/13/14-167, in the United Kingdom (Appendix A) and the Kintampo Health Research Centre Ethical Committee (IEC) in Ghana, reference number 2014-31(Appendix B). Guidelines for these boards cover the concerns with regards to carrying out health research with human participants outlined by Fontana and Frey (1994), Oppenheim (1996), Polit and Hungler (1996) and Punch (2005). They include: an explanation of any potential impact of the research on participants in advance, a description of how informed consent will be sought, and the provision of information on all features of the research, the

research procedures, planned publication of the results and confidentiality of the research data of would-be respondents or participants. Copies of the following participant materials were prepared, submitted and approved: participant information sheets, the quantitative questionnaire, the qualitative topic guide, and the consent form (Appendices C to K).

We have used a similar approach to one previously used successfully approved by the King's College London Research Ethics Committee and relevant local authorities for the 10/66 population-based surveys in LMICs. All participation, of both older participants and family informants, has been on the basis of individual signed, informed consent, other than where:

1) The older person lacked capacity to consent, for example, because of dementia. In these cases, the following established guidelines were implemented: a next of kin was asked to provide signed assent, the study information sheet was read to the older person, and if at this stage or subsequently they seemed to show distress or dissent from participation, they were not included in the study, regardless of whether or not assent by next-of-kin was provided. The next-of-kin was informed of this together with the reason for withdrawal from the study.

2) The potential participant was illiterate, in which case they were not asked to sign a document they could not read. Instead, they were read the information sheet and consent form, and asked for their thumbprint. An independent, literate witness then signed their attestation that this process had occurred, and that verbal consent had been provided.

Each participant was given an oral explanation about the study by the interviewer. Each participant had already received the information sheet explaining in simple, non-technical terms the procedures, any potential risks and hoped-for benefits (see Appendix C). The participant was given reasonable time to consider this information and to consult others as necessary.

Other than the aforementioned exceptions, each participant was asked to sign a consent form if he/she was willing to participate in the study. We first sought informed consent from the index older person, having provided them with information about the study as a whole, their potential involvement, the involvement of the other key informant for the informant interview, and the possibility that the household might be selected as a case study involving additional qualitative interviews. If the index older person declined to consent, we did not proceed further. If they did consent, we then proceeded with the interview of the older person, identified a qualified key informant, and sought their consent for the informant interview regarding the index older person. If the household was subsequently selected for the detailed qualitative case study, we approached the older person and head of household/key informant again, sought their informed consent, and that of any household members or other key informants who were interviewed.

We required the following sets of information sheets/consent forms (Appendices C and D):

1. Index older person – quantitative survey (for older person interview)
    a) for those with capacity to consent
    b) for those lacking capacity to consent (with assent form signed by a relative)
2. Key informant – quantitative survey (for a proxy version of the older person's interview and for informant interviews regarding the needs for care of the index older person)
3. Head of household/key informant – qualitative survey

All participants were provided with standard guarantees that they could withdraw from participating in the study at any stage in the data collection process, without needing to give reasons, and with no adverse consequences. If requested, we would withdraw:

a) The index older person's data upon their request.

b) The entire interview data (older person and informant interviews) upon request of the older person or head of household/key informant.

Since we were including people 70 years of age and over, we expected that a significant proportion of the index older participants in the study would have dementia – and that the prevalence of dementia could approach 10% of this population. Of course, not all of those with dementia lack capacity to provide consent. Every effort was made to explain the research in terms that would facilitate the ability of those with possible dementia to make their own informed decision. By the same token, research workers were trained to assess capacity using a functional model relevant to the specific decision-making regarding participation in the research project: had the older person understood the information provided about the project and their participation? Had they retained the information long enough to make an informed decision? Had the decision been reached independently? Were they able to communicate their decision? Procedures for capacity assessment were taught during interviewer training, using role play techniques, and a potential interviewer's performance was assessed in the field by the project co-ordinator. Difficult cases have been discussed with the researcher and local collaborators. In the event that an older person was deemed to lack capacity, assent was sought from next of kin as previously described. It was occasionally the case that a proxy version of the index older person's interview was needed to be used if the older person was unable to understand the questions or respond in a reliable fashion. In the event that an incapacitated older person would be distressed by the interview, it was be terminated immediately.

Given the vulnerable nature of the target research group (older persons aged 70 years and above and who may be frail or persons with possible dementia) and their concerned carers and family, the duration of the interviews depended on the participant's ability to cope (usually not beyond the stipulated duration of 1½ - 2hrs). Additionally, the assessment tool had incorporated skips

to ease continuous questioning and prompts for breaks if the interviewee showed signs of weariness. All participants were provided with standard guarantees of confidentiality, in that no information would be published or made accessible in such a way that would allow individual participants or households to be traced or identified or linked to the data provided.

Quantitative data questionnaires and data coding sheets identified participants by suitable identifiers only (from the HDSS) to facilitate identification of participants for the case study qualitative interviews. Names were not entered electronically, only identification numbers for each participant and informant. The original data entry coding sheets were seen by the data entry clerk and project coordinator, before being stored securely under lock and key, with only the local PI having access at the Kintampo Research Health Centre. These documents will be kept for seven years and then destroyed by shredding. Neither the data coding sheet nor the electronic data file are linked to names or addresses. We carefully anonymised all transcripts of the open-ended qualitative interviews by redacting identifying details after transcription and before translation. Digital recordings of interviews were destroyed after transcription was completed. Only the interviewer and the transcriber have seen the un-redacted interviews. Participants were informed that, in line with practice within the 10/66 Research Group and the policies of the funders of the current project, electronic versions of quantitative and qualitative data sets will be permanently archived and made available to other research groups for analysis and publication.

There were no anticipated risks for participants in this study. Other than the financial circumstances of the household (a routine and uncontroversial component of many social surveys), there are no sensitive, embarrassing or upsetting topics raised. The rationale and need for the discussion of financial circumstances were carefully explained together with the confidentiality arrangements. In the information sheet, we acknowledge the possibility that

while some people find it helpful to talk about giving and/or receiving care, others might find this difficult. This may particularly be the case when a disagreement or conflict has arisen in the past. Our qualitative interviews were carried out by a researcher who had experience in this approach, specialist training in qualitative methods and who was sensitive to such possibilities. This was done to ensure the participant was effectively guided through the open-ended interview with as little distress as possible.

The direct benefits were expected to be minimal. No incentives were given for participating in the study. However, the usefulness of their contribution in providing information that could help in mental health planning programmes in the Municipality and country were emphasised to encourage them to participate. In addition, the team emphasised the opportunity to use the information to advocate for the aged and for mental health services to be incorporated in the Municipality's health services in addition to their subsidised National Health Insurance Scheme (NHIS). We plan to provide participating households with copies of the final report summary in their local language with a suitable level of detail. Participants will be invited together with other members of the community and key stakeholders to a project dissemination workshop. We anticipate that the main benefits of the project will be indirect and may have impact in future years for for people like them who are living with older people with dementia. We aim to raise awareness among local, national and intergovernmental policymakers with regards to the burden and impact of dementia. We also hope to raise awareness more generally through effective dissemination of our findings with both local and national news media.

4.2.3. Translation of participant materials

Some components of participant materials had previously been translated into the local language (Twi) and used in studies carried out in Kintampo. This included sections in the quantitative interview marked with an asterisk, (section 4.6.1.1, Appendices H, and K). For

example, the twelve questions constituting the Euro_D Scale are derived from the GMS interview (Copeland et al., 1986; Castro- Costa et al., 2008), which had previously been translated in Twi and used to ascertain depression in the elderly in this setting. Furthermore, six questions in the Euro-D Scale were translated into Twi in Kintampo for a different study on depression (Barthel et al., 2014; Barthel et al., 2016). Hence, there existed linguistic equivalents for the words in the Euro-D Scale. Single or multiple words were used to depict words like 'fatigue' (Ɔbrɛ), 'depression' (Awerɛhoɔ) 'pessimism' (Ɛnsi yie atenka), 'guilt' (Bɔne ho ahunahuna), and were well understood for use in the same setting (Appendix I).

Translations of the following materials were carried out for the purposes of the current study: Euro_D Scale, household interview, socio-demographic and risk factor questionnaire, and informant questionnaire, qualitative interview guide, information sheets and consent forms. All translations (those carried out prior to this study and those conducted specifically for this study) were carried out according to the World Health Organisation (WHO) recommended standard translation protocol, which is translation, back-translation, and consensus methodology.

The translators worked independently and focused on their area of expertise; some on the technical terms, and others on the everyday lingua (Shah et al., 2005; Lindesay et al., 1997). They came to a consensus and ensured that the meaning and significance of words, items, content, and concepts were preserved and had equivalence with the original version that had been translated (Lindesay et al., 1997; Rait et al., 1997). The members of the team of translators comprised psychiatrists, a mental health nurse/lecturer, a traditional linguist, a language bureau scholar, and lay professionals who were based in London, (UK) and Accra and Kintampo, (Ghana).

In order to check comprehensibility, length of interview and overall acceptability, all study materials were pilot tested (Stewart et al., 2001; Ganguli et al., 1995) on four older persons in

four selected communities within the KHDSS. Materials were well understood by participants and the interviews were found to be acceptable. Therefore, no significant changes were made to study materials after piloting.

4.3 Research team composition and training

In the KHRC, there is an existing pool of staff (lay graduates) who have been trained to become experienced and dedicated interviewers. Researchers who conduct studies using the KHDSS can readily recruit and employ individuals from this cadre of staff. It is from this pool that the Director of the KHRC, together with the Administrator, recruited qualified staff to join me to interview selected participants from the KHDSS. The staff were selected based on the length of years they had worked with the population and their resulting local knowledge and familiarity with the research setting. As a result, we were able to save time and simplify the recruitment process for the field workers. Employing these interviewers for this study was also cost effective. Following this, my task was to provide the selected would-be interviewers with the requisite training to interview effectively. Training was focused on background to the research, and on specific features pertaining to the assessment tool, which was in line with the processes of the 10/66 DRG interviewer recruitment.

The research team, their qualifications and respective roles in the study were as follows:

1) PhD student (PI); who collected data and supervised field work.
2) The Research Officer (RO); with an MA in Populations Studies, assisted the PI throughout the duration of field work.
3) Four Field Supervisors; all with West African Secondary School Certificate Examination (WASSCE) qualifications, who mainly conducted the quantitative assessments in their apportioned zones.

4) Two Data Entry Clerks; also with WASSCE and Diplomas in data entry qualifications, entered the data as we collected data for the quantitative component.

Although parts of the study assessment tool have been used in this setting (section 4.6.1.1) to assess depression among the elderly, the study assessment tool in its entirety had never been used to ascertain dementia in Ghana. A structured and comprehensive training was therefore designed in agreement between the KHRC leads, a member from the 10/66 DRG and myself. While I led the training, training was overseen and complemented by the expertise of a 10/66 researcher who had conducted previous population-based studies on dementia in sub-Saharan Africa, including the use of the 10/66 dementia diagnostic assessment. This individual also contributed to the validation of the short 10/66 dementia diagnostic schedule and algorithm used in this study. This ensured that the training delivered for this study was of a similar standard to those delivered for the 10/66 DRG studies. A training manual was prepared with her guidance (Appendix C), together with the English and Twi versions of the assessment interviews for use by all trainees during the training.

Four days were required to rigorously train the interviewers for this study. We trained them in the context of the aims and methodology of the study, consenting processes, and recruitment. Time was mainly spent on the adapted short 10/66 dementia assessment, data handling and quality control procedures. Particular care and attention were given to asking the questions correctly in Twi and with the right tonal inflection to elicit relevant responses from patients and caregivers. The training included mock interviews and role-play to develop the trainees' interview and assessment skills in using the tool. One trainee posed as the interviewer and the trainer posed as the participant. All of the trainees, including the trainer, worked as interviewers in both administering the English and Twi versions of the assessment tools and in coding the

responses. This was done to ensure that each trainer understood and was conversant with the assessment tools, had acquired the required skills on how the questions should be asked and knew how to code responses directly onto the coding sheets as the responses were given in real time. The training also dealt with ethical issues and how to relate to vulnerable, frail older persons with partial speech, or impaired hearing and/or vision (Appendix C).

4.4 Sampling strategy and sample size calculation

The sampling frame was the KHDSS surveillance baseline population of 151,898, which including 4222 older persons aged 70 years or above. The section on qualitative study methodology describes our use of purposive selection for participation in the qualitative study, using the quantitative sample as the sampling frame. A reasonably large sample is required to detect a 10% dementia prevalence rate (Prince et al., 2007b), which we used to calculate the sample size for this study.

Using an anticipated dementia prevalence of 10% in the population (Llibre Rodriguez et al., 2008), a necessary sample size of 864 was estimated on the basio of precision equalling ±2% and a 95% confidence level using the formula below:

$$n = \frac{Z_{1-\frac{\alpha}{2}} \times p(1-p)}{E^2}$$

Where: n = Number of sample
Z^2 = $(1.96)^2$ for 95% confidence level ($\alpha = 0.05$)
p = "Best guess" for prevalence = 10%
E = Maximum tolerance error for the prevalence estimate (e.g. ± 0.05)

The KHDSS uses two sets of unique identifiers to distinguish among the different levels of participation: individuals are identified by the variable "*individid*" and households are identified using the variable "*socialgpid*". These identifiers were retained for the study sample. Since the sample comprised 158 villages which span a vast area (7,162 sq. km), I subsequently

obtained the GPS coordinates for the various communities and households to map out the catchment area to more readily access the households. Having the GPS coordinates facilitated the planning of our fieldwork and visits to households. After outlining travel routes to the communities and households, I observed that, due to the vast area of the KHDSS, some were too far from the KHRC (our central point of operation) by several kilometres: 49.5 km towards the outskirts of the catchment area. This would entail a 2-4 hours journey and it was highly likely that we might travel that far only to meet a single potential participant.

After several hours of discussions with the Director and other staff of KHRC, there was a consensus to use a sampling strategy which took into account: a) the vastness of the area and; b) the sources available to student; c) the duration of the entire period of field work, including other administrative processes; d) the distances between communities; and e) the times required for travel and conducting interviews. Careful consideration also went into the final sample selection to ensure the representativeness of the population would not be compromised by the estimated sample size of 864.

Given these constraints, we decided to include all eligible residents in a catchment area of a 15 km radius around the KHRC, which represents six communities in the KHDSS working area (12 sub-districts). Unfortunately, this area yielded a sample size of 856 eligible participants. It was therefore later decided to extend the sampling area to an 18 km radius, which yielded 947 eligible residents. A random sample of 44 additional eligible participants was drawn from the 16-18 km radius, as the remaining study time was not sufficient to sample the whole area (n=111 eligible participants). Since the ratio of the required sample size to the catchment population was greater than 0.05, that is ($n/N = 864/947 \sim 0.89$), the finite population correction factor was then applied to reduce the sample size to 448, which was still representative of the target population. That is, the minimum sample size required was 448. Therefore, out of a total

947 eligible individuals living within this 18 km radius, a sample of 900 was selected. The majority were located within the original 15 km radius (n=856) and n=44 from the16-18 km radius. These 900 individuals were listed and readied for interviews.

4.5 Inclusion and exclusion criteria

The following inclusion and exclusion criteria were applied to the sample population:

Inclusion Criteria

1.) Age of 70 years or above: as the prevalence of dementia is likely to be higher among older populations, this criterion allowed us to obtain a significant number of cases of dementia within our study area in the limited time dedicated to our study;

2.) Resident within the catchment area throughout the duration of the study as verified from the DSS register (i.e. stable residency in Kintampo established);

3.) Agreed and provided consent to participate (or had cosent provided by a next of kin in the case of the individual lacking capacity) after they were given study information;

4.) Able to provide either written consent and or signed/thumb printed informed consent.

Exclusion Criteria

1.) Not matched from the register (i.e. residency in Kintampo not established);

2.) Participants who were identified by the interviewers and/or the PI as being too sick to undergo interviewing and cognitive testing (ie. severe disease with a short-term high risk of death);

3.) Originally verified from the DSS register but found to have moved out or died;

4.) Identified but declined to participate.

4.6 Study procedures - approach and participant recruitment

To ensure effective use of time during the recruitment and consent period, the communities and households were listed in sequential clusters to be able to visit approximately four to six

households per day per community. For planning and mapping out routes for scheduled visits, the team considered: the time of travel to the communities; the time community members (particularly eligible participants) may be engaged in their occupations, such as leaving for and returning from their farms (planting/harvesting crops); market days; and other social gatherings e.g. funerals and others. In addition, the team decided to visit the furthest clusters of households first and worked backwards towards the clusters nearest the KHRC (the starting point).

On arrival in the various households, the RO introduced the team, particularly the student (who was new and not known in the at the time community) and presented the study aims and objectives to the household members and eligible participants. In addition, the RO explained the study to them, presented information sheets and consent forms (Twi and/or English versions) and collected them after 24 hours, allowing them enough time to decide whether to accept or decline participation (Appendices C, D and E). The team visited the households again, recruited and enrolled those who consented to participate and ensured that they or a key informant (KI) had signed or thumbprinted their consent forms. KIs were also requested to sign separate informant consent forns for their interviews.

The team invited consenting participants to schedule the time of their interviews. The team also informed them that their household might be selected to participate in a second stage of the study (the qualitative arm) for more in-depth interviews. We repeated this scenario in all of the households until we covered every compound and household where eligible participants were resident. We also followed up the first round of visits with two subsequent ones to contact the household members if previous attempts to contact them had failed the first time. After the third visit, if there was no positive response, we excluded the household.

We carried out all the interviews in the homes of the participants. Before we began an interview, we checked participants' ages (stated and documented age, age according to an

informant and event calendars) to ascertain any inconsistencies. The Index Older Persons (IOPs) and their KIs received the full assessments, which lasted approximately between ninety minutes and two hours. Information was mostly elicited from the participants. Where it was not possible to elicit responses from a participant due to severe illness, the KIs responded for the participant; this was not the case of the cognitive tests (CSI-D) and Euro_D assessments.

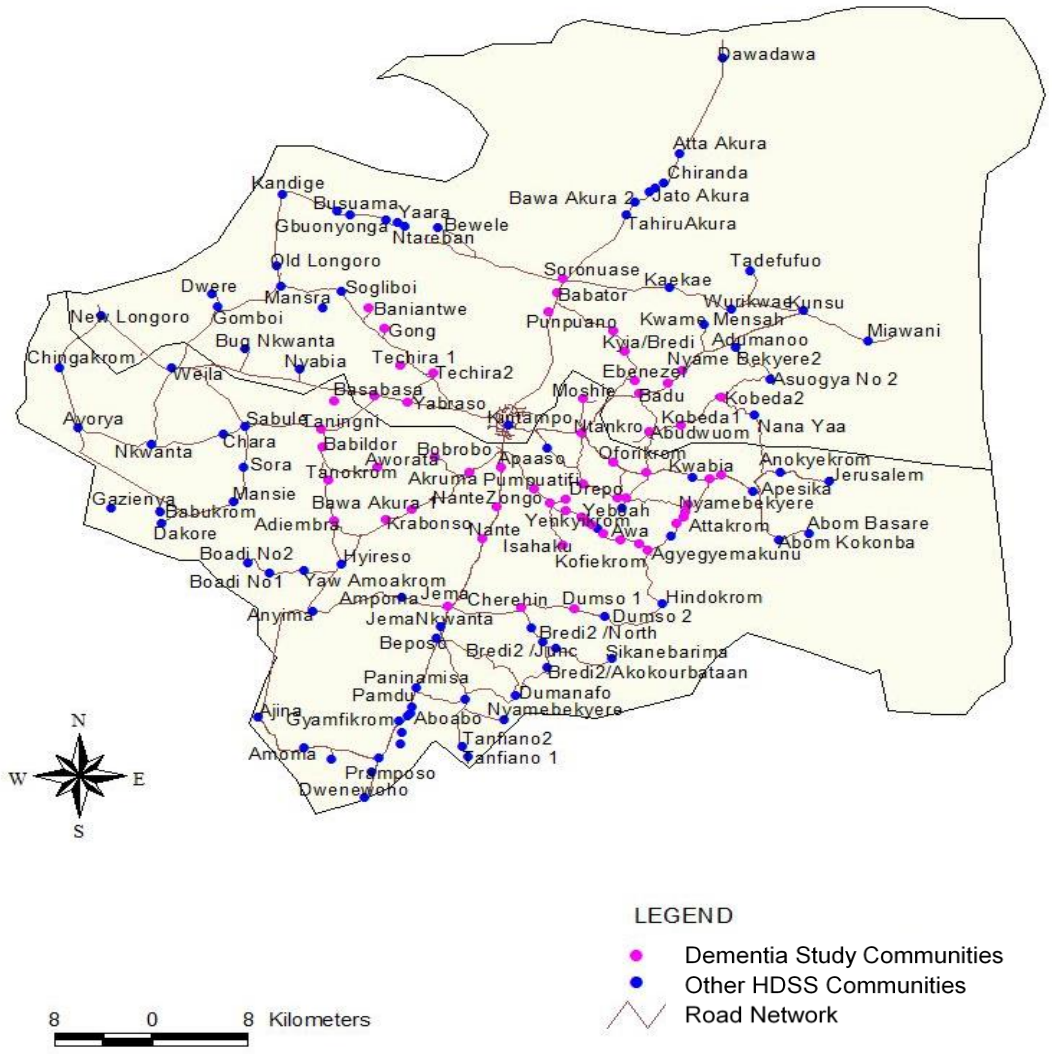

Figure 3: Map of Dementia Study Communities, KHDSS

4.7 Quantitative study

4.7.1 Measures

The study followed most of the protocol from the 10/66 DRG, which is designed to allow descriptive analyses of dementia prevalence and its associated impact including: the economic costs of illness; the relative independent contribution of dementia and other major non-communicable disorders to direct and indirect costs; disability, dependency and caregiver strain; and care arrangements. This protocol is accessible in an open-access online journal publication (Prince et al., 2007a).

4.7.1.1 Outcome: diagnosis of dementia

10/66 Dementia diagnostic schedule

To my knowledge, evidence around the use of the 10/66 dementia diagnostic schedule in sub-Saharan countries is very limited for now, comprising incomplete reports from Nigeria (Prince et al., 2007) and Central Africa (Guerchet et al., 2013) or showing large discrepancies with the DSM-IV criteria in Tanzania (Paddick et al., 2015).

As described in Chapter 2 (*2.5, page 17)*, diagnosing dementia in LMICs can present various challenges. Considering that there were low levels of literacy and educational attainment among older populations in Ghana and a lack of specialists in the area, this study used a shortened version of the original 10/66 dementia diagnostic schedule to diagnose dementia and estimate prevalence of dementia in this population.

In this shortened version of the 10/66 dementia diagnostic schedule, the Euro_D Scale replaces the GMS-AGECAT output for diagnosis. The 10/66 short dementia diagnostic schedule provides an alternative for research in LMICs, where conducting the GMS interview and/or sufficient training of interviewers may not be feasible. The GMS interview lengthens preparation for data collection as well as data collection itself; requiring 20–40 minutes to be administered to participants and 2-3 days of dedicated training for interviewers to ensure they

are able to to carry out the interviews effectively (Stewart et al., 2016). In comparison, the Euro_D Scale usually takes 3-5 minutes to be administered to participants. In the case of this study, it would not have been feasible to use the original 10/66 dementia diagnostic schedule with the GMS given the time available for the fieldwork.

The short diagnostic schedule and algorithm showed acceptable levels of performance during its development in the original 10/66 pilot test sample with 94.2% sensitivity in dementia, and with specificities of 80.2% in depression, 96.6% in the high-education group, and 92.7% in the low-education group. In survey samples, it coincided with standard algorithmic dementia classifications with over 95% accuracy in most sites (Stewart et al., 2016).

Essential parts of the schedule (required for the 10/66 dementia diagnosis algorithm) include:

1) A cognitive test battery comprised of the Community Screening Interview for Dementia cognitive tests (CSI-D) (Hall et al., 1993), which have incorporated the Consortium to Establish a Registry for Alzheimer's Disease (CERAD), an animal naming verbal fluency task, and the modified CERAD 10 word list learning task with delayed recall (Ganguli et al., 1996);
2) The Euro_D Scale for depression screening;
3) The CSI-D Informant Interview (RELSCORE), investigating evidence of cognitive and functional decline from informant reports, an additional detailed extended interview of the informants about the onset and course of the condition.

Details of these essential parts are provided below.

Community Screening Interview for Dementia (Hall et al., 1993)

The *CSI-D cognitive part* is an approximately 30-minute questionnaire administered to participants measuring: memory, abstract thinking, judgement, and other disturbances of

higher cortical function (apraxia, aphasia, agnosia, and constructional abilities). A cognitive score (COGSCORE) is calculated from the participants' cognitive tests with different weighting applied to different items with a low score indicating cognitive impairment. As it was developed for use in LMICs, items relevant to space and time orientation include alternative formulations in order to be adapted to the setting of the study (i.e. name of chief vs. name of city; name of reserve vs. name of province; name of nextdoor neighbours vs. street address of home, among others). The most relevant options were chosen here for the Kintampo area (see Appendix H). For the animal naming verbal fluency task, participants were encouraged to name as many different animals as they could in 1 minute.

Two items testing the visual-constructional abilities of participants required them to draw geometric shapes. However, as most of the participants in this study were expected to be non-literate, their visual-constructional ability (praxis) was assessed using the Stick Design instead (Baiyewu et al., 2005). The Stick Design test was developed in Nigeria and was derived from the WHO Construction Test of the larger Cognitive Battery of Cognitive Assessment Instruments. The Stick Design options were: 1. Square; 2. Triangle with stem; 3. Chevron; and 4.) Rake-like figure. After the interviewer demonstrated how to construct the model, two design options were selected for participants to construct consecutively (Figure 4): the square (1) and the rake-like figure (4). With the knowledge that the participants would be given the Stick Design Test, interviewers asked the participants to identify a colour of a piece of clothing, to point towards or hold an item at a reasonable distance, or to point towards an item not too far away from him/her, which included the matchstick. This was done to rule out vision impairment and to make sure they will be able to identify and see the matchstick. One specific question for the matchstick was to indicate "if the matchstick head was up or down"? If they visually identified the items, the Stick Design Test was performed. For demonstration, the interviewer arranged the wooden matchsticks on a flat surface (stool/table/wooden bench,

provided by participants), clearly emphasising the need to correctly position (see Figure 4) the matchstick and copy the stimulus. Each participant was then given four matchsticks and asked to make the exact representation of the design stimulus (Appendix H). This action was repeated for each design arrangement. A correct representation was score as "1" and an incorrect representation was scored as "0" (Baiyewu et al., 2005).

Figure 4: The stick design test (Baiyewu et al., 2005).

The *CSI-D Informant Interview* is designed to elicit evidence of cognitive and functional decline, as well as personality changes at work and the social relationships of the participants. It is comprised of 26 items and takes approximately 15 minutes to administer. A high informant score (RELSCORE), which is the total unweighted score from the informant interview, indicates functional impairment.

The discriminant function score (DFSCORE), a weighted score combining COGSCORE and RELSCORE, can be categorised into "good performance", "intermediate performance" and "poor performance", providing levels of probability of dementia. COGSCORE and DFSCORE have validated cut-off points for "probable", "possible" and "non-cases" of dementia, estimated by applying a series of regression coefficients linked to outputs generated from the above measures (Stewart et al., 2016; Prince et al., 2003; Rodriguez et al., 2008).

The modified CERAD ten-word list learning task

The ten word list was developed in the Indo-US Ballabgarh Cross-National Dementia Study (Ganguli et al., 1996) and then partially adapted for the study in this setting. It comprised seven of the English words retained from the CERAD battery list: arm, letter, queen, ticket, grass, stone, and stick. The remaining three (butter, corner, and book) were replaced with soup, veranda, and cutlass. These adaptations were made in consultation with bilinguistic personnel (including one of the translators for the assessment tool) and deemed more culturally and educationally sensitive (Prince et al., 2003). The word equivalents were deemed to be more suitable because they were commonly known but not too easy or too difficult for recall and were therefore appropriate in this setting. Soup, prepared in a variety of ways, is among the most common meals eaten regularly in Ghana, and even more so in a rural environment. A veranda is a shaded section of the front part of a house, and is used commonly in a rural setting for relaxing, sleeping, and receiving visitors. A cutlass is a farm implement and a well-known word in both rural and urban settings. It is used together with the hoe by crop farmers for weeding and cutting down crops and shrubs, etc. It is also commonly used as a butcher's knife to cut things that the ordinary kitchen knife is unable to. In the learning task, the 10-word list was read out to a participant who was immediately asked to recall the words he/she remembered. This process was repeated three times and a total score out of 30 was given. After five minutes, the participant was asked to recall the 10 words to give a delayed recall score of out of 10.

The EURO_D scale

The structured Euro_D 12-item depression screening scale was used to assess depression in participants in this setting. The Euro_D Scale has been extensively applied and assessed in both developed and developing countries (Stewart et al., 2016). It has also been used in a rural

setting of South Africa to assess the prevalence of depressive symptoms. However, in the latter study, only three out of the twelve questions were used (de Jager et al., 2017), whilst its entirety is included in the 10/66 short dementia diagnostic schedule.

The scale was derived from individual items that were extracted from the GMS interview. The Euro_D can be administered to ascertain how participants may have felt over the past month with questions on symptoms of depression, pessimism, suicidality, guilt, sleep, interest, irritability, appetite, fatigue, concentration, enjoyment and tearfulness (Appendix I). These generated responses were grouped by quartiles of 4 categories; "0", "1-2", "3-5", and "6". These scores replace the GMS-AGECAT output required in the algorithm used with the short 10/66 diagnostic schedule to assign probable dementia.

Preliminary processing of the data from the Euro_D showed unexpectedly high scores on the depression scale compared to other settings where the 10/66 diagnostic schedule was used (including other African settings), whilst the standard deviation was similar (5.50 ± 2.23 vs. 2.48 ± 2.42). This resulted in the identification of 17 participants with probable dementia in the first iteration of the brief algorithm. A high proportion of missing values on items from the Euro_D was also observed. A measurement bias, more likely due to interviewers' issues, was suspected rather than a true difference in the frequency of depression in this population (which would have been greater than 50% in this case). As the Euro-D scores are processed in the 10/66 dementia algorithm, after extensive discussion with the team who designed the 10/66 dementia diagnostic assessment (both original and short forms), it was decided that Euro_D scores should be adjusted (correcting for the error, i.e. substracting 3 – the difference between mean scores observed in the 10/66 other population-based studies and mean scores from our sample).

10/66 Dementia brief diagnostic algorithm– known limitations

The main dementia outcome in this study was defined as those scoring above the cut point of predicted probability of dementia according to the 10/66 brief algorithm (Stewart et al., 2016). The algorithm uses coefficients from the Euro_D, CSI-D informant and cognitive test interviews and from the modified CERAD 10-word list learning tasks. However, cognitive impairment can also be caused by toxic or metabolic dementia, HIV-associated neurocognitive disorders (HANDs) or delirium. Accurate differentiation of types and levels of cognitive disorders can only be done clinically (Caplan & Rabinowitz, 2010). Due to the lack of available specialists in the area at the time of the study, no further validation against clinical criteria or clinical assessment of the participants identified through the algorithm was possible. Therefore, any reference to dementia in this study should be understood as *probable dementia*.

4.7.1.2 Background and risk factors

Detailed information was collected using a set of standardised questionnaires from the 10/66 study protocol on risk factors and conditions that may potentially affect or be associated with dementia, as well as current circumstances, impairments, care arrangements, carers strain and economic costs. Details are provided in the sections below.

a) *Household questionnaire*

The household questionnaire is a brief questionnaire collecting information on participant's age, the household composition (those who live in the household) as well as some indicators assessing household wealth. It also collected the names of contacts to facilitate the tracing of participants at a later date. The responses were given by a household member other than the IOP.

The determination of the correct age of people in sub-Saharan countries, where a lack of reliable documentation or well-established systems of birth registration is frequent, can be quite challenging, especially for those born before independence. Inaccuracies in the age of persons

participating in epidemiological studies may therefore be a source of bias, especially among older populations (Paraiso et al., 2011). In the household questionnaire, age was formally ascertained using 3 different sources: stated age of the participants, the age recorded on any official documentation, and the age according to an informant. In the event of that discrepancies between those sources being greater than two years and not adequately explained, or when the information was not available, age was estimated according to an events calendar relevant to the local community, eg. Including well-known national events:

- The building of the Kintampo Police Station – 1923;
- The beginning of the 2nd World War – 1939;
- The end of the 2nd World War – 1945;
- The Fight between the Mo and the Nafaana – 1946;
- Ghana's Independence Day – 1957 (6th March);
- Dr. Kwame Nkrumah's first visit to Kintampo – 1957 (28th October);
- General Mitchel Plane Crash – 1962.

Household living arrangements included the number of co-residents and the availability of children/family for support. In addition, household assets (car, television, refrigerator, plumbed water supply, connected electricity, telephone, plumbed inside toilet, plumbed inside bathroom) were collected. Based on this, an asset index was categorised per quartile, with 1st quarter = least assets and 4th quarter = most assets. Food security was also assessed and used during the analysis ("ever gone hungry because there is no food to eat", "how many times has it happened", etc).

b) Background socio-demographic and risk factors questionnaire

This questionnaire exists in two versions: one with questions addressed to participants and another one with the same questions addressed to informants. The informant version was administered when the information from the participants was incomplete or might not be reliable. The questionnaire elicited information on 12 main categories: early life; current circumstances (e.g. head of house); social network; socio-economic status; health; impairment; pain; disability; reproductive health (e.g. sex, age at menarche…); behaviour and lifestyles (e.g. smoking…); health and use of services. The main variables collected are detailed below.

- ***Socioeconomic variables***

- ***Marital status:*** indication by participants that they were never married; married or cohabiting; widowed; or divorced.
- ***Domicile status:*** residence at birth; during childhood; and adulthood.
- ***Level of education:*** categorically determined as none; minimal; completed primary; completed secondary; completed tertiary.
- ***Literacy:*** was tested using a short sentence: 'Ama went to school', that had to be written or read out by the participants. The participants' responses were then categorised into three options: "no" (coded 0) – for those who participated in the exercise but were unable to read; "yes" (coded 1) – for those who also participated in the exercise and were able to read out/write the text given to them; and "." - and missing values were attributed to the participants who refused to participate in the literacy exercise.
- ***Religion*** - affiliation and practice.
- ***Social network in the community*** – information about social activity and social support, was obtained.
- ***Occupation:*** "best occupation" (i.e. the highest occupation they had in terms of socio-economic status) for the participant, as well as current occupational status.

- ***Health conditions***

Participants' physical health was assessed using self-reported diagnoses, which were: stroke; hypertension; diabetes; and physical impairment. The "self-reported" aspect signified that the diagnosis was a known fact to the interviewee and their family, backed with evidence that the interviewee had been diagnosed by a clinician of any of the above listed conditions and fourteen other commonly occurring impairments (Duke, 1978).

- ***Stroke*** - was ascertained with the question: "have you ever had a stroke that needed medical attention?" If the answer was "yes", they were then asked to describe "what happened?" The answer was coded positive only if the participant or informant gave a clear history of sudden onset of unilateral paralysis and/or loss of speech and/or blindness lasting for at least 24 hours to exclude previous transient ischaemic attacks. If the history was supportive of stroke they were asked "who diagnosed this stroke?" (no one/primary healthcare worker/specialist). Stroke was coded only if a clinician had made the diagnosis.
- ***Hypertension*** - ascertained with participants' self-report ("have you ever been told that you had high blood pressure? When you were first told? Were you started on treatment? Are you still on treatment?"). A response was coded only if a diagnosis was made by a clinician and treatment started. No blood pressure readings were taken.
- ***Diabetes - self***-reported, when a medical diagnosis of diabetes had been made by a clinician. A response was coded for 'yes' to the question ("have you ever been told by a doctor that you have diabetes?").
- ***Physical impairments*** - self-reported physical impairments, categorised as having 1-2 or and three or more of 15 limiting physical impairments (arthritis or rheumatism; eyesight problems; hearing difficulty or deafness; persistent cough;

breathlessness, difficulty breathing or asthma; high blood pressure; heart trouble or angina; stomach or intestine problems; faints or blackouts; paralysis, weakness, or loss of one leg or arm; malaria; tuberculosis; skin disorders, such as pressure sores, leg ulcers or severe burns). Impairments were rated if they interfered with activities "a little" or "a lot", as opposed to "not at all" (Fillenbaum & Smyer, 1981).

- ***Reproductive status (for women)*** - responses were coded on menarche; menopause; reproductive period; and their number of children.
- ***Head injury*** - self-reported head injury accompanied by loss of consciousness.

- ***Disability***

Disability was measured using the WHO-DAS II (Üstün, 2010). This study used the 12-item version (a 36-item version is also available). This measures activity limitation and participation restriction. It was specifically developed by the WHO as a culture-fair (i.e. cuts across cultures and is culturally relevant across cultures) assessment tool for use in cross-cultural comparative epidemiological and health services research (Sousa et al., 2010a).

- ***Behaviour and lifestyle***
    - ***Smoking*** - smoker; ex-smoker; non-smoker; length of exposure; type of tobacco used (cigarettes, pipe tobacco, chewing tobacco (dried), chewing tobacco (fresh), snuff); average quantity taken per day; age at start of habit; and age when the person quit, if the habit was interrupted.
    - ***Alcohol consumption*** - number of units ingested per week, before and after the age of 65 years. To determine hazardous drinking before age 65, a cut off level was established. The maximum usual consumption per week was recorded in units of alcohol: 14 units/week for women and 21 units/week for men. The maximum usual consumption per week was recorded in units

of alcohol, by type of drink: one glass of beer - (250 ml = 2 units); one jug of draught beer - (750 ml = 6 units); one calabash of pito/palm wine - (750 = 6 units); one Fanta bottle of pito / palm wine - (330 ml = 2.64 units); one shot of liquor or Akpeteshie - (22 ml = 2 units); one glass of wine or sherry - (175 ml = 2 units); and one bottle of liquor - (1000 ml = 32 units).

- ***Use of services*** **-** these were determined by asking questions about consultations with government primary care providers (primary care staff, hospital doctors, and/or other health workers e.g. physiotherapists, nurses, etc), private health care providers (private doctors, dentists, and/or traditional healers). Responses were elicited to assess the number of visits in the last month, whether participant was accompanied, time (minutes) of travel, travel cost, time (minutes) spent with care providers, average cost of primary care visits, number of visits to health care providers in the last 3 months, whether they were admitted for inpatient treatment, days of admission, cost of admission, the use of medicines in the last 3 months, and the total cost of medicine used in the last 3 months (*all costs in Ghanaian Cedis*).
- ***Health insurance*** **-** this refers to the National Health Scheme, a government-subsidised health insurance, which is subscribed to by all citizens in the country, and is government-subsidised health insurance; this was determined by interviewer assessment after asking questions to ascertain if they had subscribed to and held a subscription card. It sought to ascertain whether the subscription covered individuals and/or their families, and what the subscription/renewal cost was per annum.

c) ***Informant questionnaire***

This questionnaire comprises of three modules.

- **The background module** was administered in full to all informants and provided information about the informant, including:
    - ***Economic impact*** **-** which was assessed using the Client Service Receipt Inventory for information on type and cost of accommodation; income from all sources for the person with dementia and their caregiver; the occupation of caregiver, and so on.
    - ***Practical impact*** **-** contact time between the caregiver and the cared for person, measured as time spent by the caregiver in the last 24 hrs in specific caregiving activities, such as communicating, using transport, dressing, eating, looking after one's appearance, and supervision.
    - ***Mental health of the caregiver*** **-** the mental health state of the caregiver measured with the *Self-Reporting Questionnaire 20* (SRQ 20), a 20 item scale of symptoms of common mental disorder (anxiety, depression and somatisation), (Mari & Williams, 1985). A score of 8 or above signifies clinically significant morbidity.
- **The care module** provided information about care arrangements and the impact of providing care on caregivers (an adult who assisted index older person in their daily activity). This was done to sketch out the family network, establish if the older person needed and/or received any care from family members or others; identify who was responsible for organising and providing 'hands on' care; establish whether the informant was involved in organising care/providing 'hands on' care, and if so, whether he/she was one of the main caregivers.

- ***Dependence*** **-** was determined by interviewer assessment after a series of open ended questions on care arrangements with a key informant – "who shares the home?"; "what kind of help does the participant need inside and outside the home?"; "who in the family is available to care?"; "what help do you provide?"; "do you help to organise care and support?"; "is there anyone else in the family who is more involved in helping?"; "what do they do?"; and "what about friends and neighbours, what do they do?". The interviewer coded whether the participants required "no care", "care some of the time", or "care much of the time".
- ***Caregiver economic strain*** **-** sought to elicit whether the caregiver had "cut back" or "stopped" work in order to provide care.
- ***Caregiver psychological strain*** **–** was appraised with the 22-item *Zarit Burden Interview (ZBI);* this took assesses the carer's appraisal of the impact that their contribution has on their lives (Zarit et al., 1980; Zarit et al., 1986). Each item is quantified as "0" (no burden) to "4" (highest burden).

- **The informant module** provided clinical information about the older person from the perspective of the informant and investigated aspects related to the informant's strain and mental state. Information on cognitive and functional impairment was collected through the Informant Interview of the CSI-D and included 26 items. When the total score for this section of the CSI-D was 2 or less, the interviewer skipped to the assessment of *Behavioural and Psychological Symptoms of Dementia* using the information elicited on the *Neuropsychiatric Inventory Questionnaire (NPI-Q)* (Kaufer et al., 2000). If the total score was 3 or more, the *History and Aetiology Schedule – Dementia Diagnosis and Subtype (HAS-DSS)* (Dewey &

Copeland, 2001) was performed. This instrument includes items investigating the onset, course of illness and occurrence of other mental phenomena (delirium, behavioural and perceptual disturbance, and depression), as well as items investigating physical health and other factors for secondary dementia.

4.7.2 Data management

The catchment area was zoned into four sections and each section assigned to an interviewer to administer assessments to participants resident in the sectioned area. The assessments were coded directly onto paper sheets by all interviewers. Assigning a zoned area to each interviewer resulted in a smooth supervision process. Both the RO and I supervised the four interviewers, which involved scheduling to be with one interviewer per week in their individual zone and participating in the administration and coding of the assessments in each scheduled home of the participants. During the fieldwork in the first month, we held weekly debriefing sessions to review our experiences and the difficulties we encountered. These sessions included dealing with administrative considerations, scoring of interview assessments as well as noting any adverse or interesting incidents that had occurred. Subsequent debriefing sessions were held fortnightly till the quantitative data collection ended.

Two members of the team (RO and PI) manually checked all survey data, which was collected daily to maintain the integrity of the data. This enabled us to rectify any discrepancies and inconsistencies with dates, numbering, missing values, etc., on the coding sheets. The coded forms were then submitted to the computer centre (CC) for batching and data entry. The data entry clerks entered the data into Epidata® entry files using a double entry method and saved the data on a main server at the Data Management Centre, KHRC. A supervisor supporting the data entry clerks checked the entered data and any errors regarding incorrect coding were referred back to the interviewing team for correction. A copy of the final dataset was forwarded

to an expert from the 10/66 DRG in London by email as attachment fortnightly to also double check for consistency and detect any unusual distribution in the data. It also allowed for backup copies of the data to counteract any local data loss through software failure, accidental deletion or computer failure. The Epidata® files facilitated data processing, data merging and archiving. The data was extracted into SPSS® and processed using the 10/66 command files. The processing entailed cleaning, processing and labelling the data set of derived variables, which were exported into other statistical programmes (Prince et al., 2003) for analysis.

4.7.3 Analysis

SPPS Statistics version 22 was used to process the 10/66 dementia diagnostic algorithm and Stata Software version 13® was used to conduct all statistical analyses. The primary outcome for analysis in the quantitative component of the work was probable dementia, as given by the 10/66 dementia diagnosis algorithm and was analysed used as a binary variable. Prevalence of dementia and its 95% confidence interval (95% CI) was estimated overall, and by sex and by age groups. Prevalence was also standardised against the SSA distribution of the population. Univariate analyses were carried out to determine the frequencies and percentages of the variables under study. Box plots were used to examine the distribution of cognitive, RELSCORE, depression and disability scores. Mean scores and a standard deviation of disability (WHODAS) were also established. Bivariate analyses were conducted using the Chi-square test of association between background characteristics, whether or not individuals were respondents or non-respondents, and for those with and without probable dementia.

Differences in the distribution of cognitive, informant, depression and disability scores among those with dementia vs. those without dementia were tested using Wilcoxon Rank sum tests. Poisson regression with robust standard errors was used to examine the differences in the prevalence of dementia across age and sex as well as several other variables of interest.

Multivariable regression models reporting prevalence ratios were used to determine the associations between dementia and demographic and socio-economic factors, needs for care, and disability. The zero-inflated negative binomial regression model was used to examine the effect of dementia on disability.

4.8. Qualitative study

Qualitative research methods are well suited to the exploration of how meanings are constructed in everyday life, especially when the meanings and processes under study are not agreed on. A qualitative research approach involves the study of personal narrative accounts and how individuals make sense of, and give meaning to, their experiences (Ormston et al., 2014).

The qualitative component of this thesis provides context to the quantitative study and enables expansion of the themes investigated using quantitative methods by exploring the experiences of people living with dementia and those of their caregivers, with the aim of gaining insights into beliefs, perceptions and understandings of the condition. The qualitative study was comprised of a series of case studies of households of older persons living with dementia and their family members, as identified from the quantitative component. Participants took part in in-depth interviews to allow them to narrate their own experiences and perspectives, or "tell their own story".

4.8.1 Case studies

The case study is among a variety of methods that are ideal to use when the research questions focus on the "how" and "why" of the study. According to Schramm (1971), the case studies approach is used "to illuminate a decision or set of decisions; why they were taken, how they were implemented, and with what results" (Schramm, 1971). In defining what a case study method is, Yin states it is: "[…] an empirical inquiry that investigates a contemporary

phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (Yin, 1984:23).

For this qualitative component, the main aim was to obtain multiple in-depth perspectives, from both the person living with dementia and family members involved in their care, their including perceptions and behaviours regarding dementia in their natural context. This method highlighted, for example, detailed information from the elderly persons and their families on "how" they coped, "why" they made particular decisions and their choices in action (Yin, 2009). The qualitative study offered important evidence to complement the quantitative component; in particular, it expanded our understanding of mechanisms for quantitative associations between carer strain and dementia. The case study approach has been previously and successfully used in the 10/66 DRG INDEP studies in Peru, Mexico, China, Nigeria (Mayston et al., 2014), Norway (Smebye et al., 2012), and by another research team in Tanzania (Mayston et al., 2014; Mushi et al., 2014).

4.8.2 Selection of participants and households for interview

As described earlier in this chapter, 17 older people screened positively for dementia by the end of screemomg using the first iteration of the algorithm, at the time when the qualitative study was due to start. These first 17 participants were therefore used as the sampling frame for the qualitative study. A sample of 40 total participants (with a maximum of four from each household, including diagnosed IOPs) was estimated as a sufficient number which would approach saturation on the main themes of the interviews. Equally, in the context of a PhD project using both quantitative and qualitative methods, conducting 40 qualitative interviews was considered to be the limit of what was feasible within the timeframe and scope of the project.

The objective of our qualitative study was to explore how dementia was understood, care was arranged, and the dementia condition was managed. The aim of purposive sampling was therefore to achieve diversity of participants' perspectives and experiences. The variables we focused on were informed by a review of the literature as likely to have an influence upon the main themes: sex, age group composition and household size. We selected a shortlist of ten candidates for qualitative interviews, with the aim of representating the perspectives of different sociodemographic groups.

i. *Sex:*

We hypothesised that gender was likely to have an impact upon the dynamics of care arrangements for the elderly in this setting. The initial 17 positively screened IOPs comprised 13 women and four men. As a result, we included all of the men and six of the women to represent the total number of households: 48% of the quantitative sample were female.

ii. *Age group*:

Age was included to reflect the range of age categorisation used in quantitative component, as required in maximum variation in qualitative sampling (Creswell, 2014).

iii. *Household size and structure*:

The sizes of the households in our case studies ranged from two to ten co-residents which we used to determine household size as either small or large. We documented the composition of the housholed in terms of family members (nuclear and/or extended), and/or tenants living with the IOPs who may offer social support to them. The household should have the main hands-on caregiver (primary caregiver) providing care financially and/or physically living in the household. The structure reflected the number of different household arrangements, regarding who were residents in the household with the IOP, their relationship with the IOP, and which persons might be eligible to be included in the interview.

4.8.3 Development of topic guide

The 10/66 DRG INDEP topic guide was used as a starting point for the development of the topic guide for this study because of our focus on the lived experience of dementia, including decisions about care and care arrangements. The 10/66 DRG INDEP topic guide was designed to elicit narratives about the experience of old age dependence from older dependent people and their families, in order to gain an understanding of the economic and social effects of care dependence of older residents across sites in four LMICs (Mayston et al., 2014).

Interviewing took a narrative approach (Mayston et al., 2014). A guidance approach enabled the older people and their caregivers to naturally "tell their stories" uninterrupted (Jovchelovitch & Bauer, 2000; Muylaert et al., 2014). This approach was found to be both feasible and acceptable in the INDEP study, as well as in the pilot interviews for this study, and resulted in rich, coherent narratives from participants (Mayston et al., 2014). Used in the context of a case study framework, this style of interview uniquely allowed a comparison of perspectives across different agents involved in the care and experience of living with dementia. The INDEP interview guide was amended to include Kleinman's explanatory model interview questions (Kleinman, 1980) in order to focus interviews more specifically upon experiences, understandings and aspects of care of those living with the condition (objectives *3* to *5*) (Appendix L**).**

The two-part topic guide framed the primary area of investigation with open-ended semi-structured questions. It set the tone of interview with the introduction of the topic at hand and explained the form the interview would take. We then proceeded step by step to question the participants in order to find markers that pointed to other areas to explore (Mears, 2012). It included relationship mapping of important people related to the family (Appendix M), carried

out with the head of household or key people identified within it. To elicit their narratives, we used an outline script with prompts.

The prompts were included to probe for responses related to our topics of interest that were not covered in the narratives or where the interviewer felt the expansion of a particular theme would offer helpful insights.

The two-part guidance method we used is summarised below:

Part 1 - *The 10/66 INDEP:* this was comprised of introductions to put respondents at ease and to map out household relationships (Appendices L, & M) to get an idea of the important people related to the family (four main questions); main narratives with general prompts to lead to in-depth storytelling about the onset of the older person's condition; and the impacts of this condition on their lives. The interviewer made notes (Appendix N) and asked specific questions and prompts about particular areas of interest or key events if these were not included in the initial narratives.

Part 2 - *Kleinman's Explantory Model of Illness Framework (1980*): this was comprised of eight questions to elicit explanatory models of dementia from people living with dementia and the members of their households.

4.8.4 Procedures for interview

With coordination and guidance from qualitative experts, we selected the households for in-depth interviews (IDIs) and subsequently began the processes for the IDIs; we started this process after approximately two-thirds of the quantitative data had been collected and checked for completeness and diagnosis of cases. This allowed the IDIs to commence and be completed within the study timelines. The ten households selected for our case studies were grouped according to the area codes of the communities and their physical locations. This was done to

enable us to use the limited resources effectively, including travel time to the various communities. The IDIs began in September 2015 and were concluded in October 2015.

The RO accompanied the PI to all of the households selected for the IDIs. This was to mitigate any situation related to the gender of the PI which might arise regarding the conduct of interviews. We introduced ourselves once more to the interviewees as a formality and attempted to create a comfortable and relaxed atmosphere through general conversation. Participants had been informed during the quantitative study that their households might be selected for a second interview during the introduction to the quantitative study (section, 4.2.2). Nonetheless, the study was again introduced to the participants and explained in a way so as to highlight the difference between the first set of interviews and the current one about to be conducted.

In order to identify key members of the family or household who were involved in caregiving with regards to practical work, financial contribution, or decision-making, a relationship-mapping exercise was carried out with the head or key member of households at the start of the interviews. The mapping exercise included identifying individuals both within and outside of the household who were involved in caregiving. On the basis the findings from this exercise, individuals were selected to participate as interviewees. The participants were assured that the interview would take place in the form of a conversation and that it would be carried out on the participants' terms. This was done to create an environment conducive for the participants to share their stories (Willig, 2013).

The interviews were conducted face-to-face in the selected households with the selected key participants involved in the care of the older person and with the older person themselves where possible. All ten IOPs were in attendance during the interviews. The IOPs sat slightly apart but always within earshot and contributed and or participated when they felt so inclined. Two other

family members who were not living in the same household, but were actively involved in the older person's care, were included and interviewed separately on different days at their choice of venue.

It is important to note that, in this setting, it was extremely difficult to interview a participant alone. For them, a research project solely interested in their older relative was a novel idea. Other co-residents (nuclear/extended family members) were curious and keen and, therefore, gathered near enough within the compounds of the households to either observe and or contribute to the proceedings. For this reason, the interviews were often conducted in small groups comprising three to five family members (nuclear/extended) in the households so as to maintain a good rapport with interviewees and to not alienate the others. We also allowed this in order to conform to their norms and values of communal living. This gave other household members who were not selected as interviewees the opportunity to contribute information spanning a broader scope and adding more depth (Ritchie et al., 2014) to the interviewees' narratives.

All interviews were conducted in the local language (Twi) and audio recorded with the permission of participants. Field notes including key words, phrases, and key events of the lives of members of the household, the decisions they make and effects on the household finances regarding these events were taken and included in the transcripts to supplement the data. Interviews were discontinued when no new "stories", "themes", or "issues" emerged per our *a priori* topics.

4.8.5 Pilot in-depth interview

Prior to the in-depth interviews, the RO and the PI conducted a pilot in-depth interview in one household. This was done to ensure that the topic guide worked in terms of eliciting the *a priori* themes. It was also done to test the feasibility and acceptability of conducting qualitative

interviews with this group of people, as well to ensure our procedures, including transcription and coding, were sound and to start to develop a framework and estimation of how long each of these tasks would take. In general, the topic guide was found to work well - we made no amendments and therefore incorporated these interviews into the main dataset.

4.8.6 Approach to data analysis

Several methods for undertaking qualitative data analysis exist (Miles et al., 2014). These can be categorised under three methods: social-linguistic methods, which explore the use and meaning of language, for instance discourse and conversation analysis; those that focus on developing theory, which are characterised by the use of grounded theory; and those that describe and interpret participants' views, such as content, thematic, amd framework analytic methods (Smith & Firth, 2011). The framework analysis was considered appropriate because the study draws on existing results from our quantitative findings, and allowed for further findings to emerge through content analysis, based on our study objectives.

4.8.6.1 Data management

Data from qualitative studies often comprise voluminous transcripts of hours of audio recordings, notes and/or written documents, which need to be organised to bring order, structure and meaning to the raw data. This activity is termed data management (Ritchie et al., 2003). Though the process of managing qualitative data may be time consuming, it is a necessary activity, which initiates the analytic process. According to Ritchie et al., (2003) and Spencer et al., (2014), analysis begins at the data management stage, with a process of familiarisation and subsequent labelling and sorting of data (Spencer et al., 2014; Ritchie et al., 2003).

The raw data for this qualitative component was comprised of interviews transcribed verbatim in English from Twi and field notes and mapped relationship charts (Appendix M). During transcription, some subtleness in the language, e.g. pauses or laughter, were retained to ensure the transcript remain true and realistic to the tone of the participants (Braun & Clarke, 2006; Willig, 2013). These transcripts were initially saved as Microsoft Word documents.

4.8.6.2 Transcription

Each interview was transcribed daily from Twi directly into English using Microsoft Word. The RO completed a first draft. The PI then played back and listened carefully to the recordings, checked and corrected errors, filled in missing texts and tidied up the first drafts. A third person, who is an expert in qualitative research and is well versed in written and spoken Twi, also read the transcripts, listening in parallel to the interviews to ascertain the that the translated transcriptions were realistic before the first drafts were finalised. We took care to ensure that the accurate accounts of participants were presented. This was important in order to ensure that the voices of participants were resonant in the transcripts. When all of the interviews had been transcribed and typed in English, the student's second supervisor, RM, randomly selected some of the transcripts of the completed version in English and also read through.

4.8.6.3 Analysis process

Analysis involves organising data by examining and fragmenting it into parts and reassembling these part back into a coherent form (Creswell, 2014) in order to explain the social phenomena under study. According to Miles et al., (2014), qualitative analysis activity is continuous and iterative and follows in three ways; 1) "data condensation" - selecting, focusing, simplifying, abstracting, and/or transforming the data that appear in the full corpus (body) of written-up field notes, interview transcripts, documents and other empirical materials; 2) "data display" -

an organised, compressed assembly of information that allows conclusion drawing and action and 3) drawing and verifying conclusions" (Miles et al., 2014).

4.8.6.4 Framework analysis

Framework analysis is one of thematic methods used in qualitative analysis. Thematic methods identify what is common as well as what is different in the data and link these to describe and explain (Gale et al., 2013) the patterns within and across the data (Braun & Clarke, 2006). The framework method was created and developed by specialist qualitative researchers working in social research policy and has been in use since the 1980s (Furber, 2010; Gale et al., 2013). It was developed for analysing vast amounts of data generated in qualitative research and to also understand important aspects of social behaviour in order to inform social policy for its application in society. The emphasis of the framework approach lies in making the procedure of data analysis transparent and illustrative by linking each stage of analysis (Braun & Clarke, 2006).

Furthermore, it is a matrix-based analytic approach that is flexible and follows a distinct five-stage, step-by-step procedure (familiarisation process; developing a theoretical framework; indexing; charting; and synthesizing), which interconnects each stage to develop a rigorous and systematic framework (Furber, 2010). The framework approach also works alongside case analysis and helps identify cross-cutting themes in the data (Feilzer, 2010; Gale et al., 2013). Therefore, this is particularly relevant for the type of data obtained in this study, given that it includes multiple perspectives on the same "case" (IOP with dementia), as well identifying common themes across the experiences of caregivers and people living with dementia.

The framework process allows the development of a coding framework which incorporates *a priori* themes identified from the literature in addition to new codes which emerge from the

data. This was a good fit with this study, given its focussed nature and its location within a mixed method study with clearly defined *a priori* topics of interest and research questions, aims and objectives. The steps involved in framework analysis enable the researcher to understand and interpret the structured summarised data it produces (Gale et al., 2013; Furber, 2010).

4.8.6.4.1 Familiarisation process

This is the first stage of data analysis. It involved immersing myself in the contents of the interviews to be completely familiar with the data to develop an overview of the main ideas involved (Ritchie & Lewis, 2003). To ensure that I was familiar with the data from the onset, data immersion in the first interviews started along data collection and the transcription of the interviews. Immersion involved engagement with interview contents, e.g. listening to the audio-recorded interviews and reading memos, which included reflective notes and impressions in the transcripts written on the field. Being conversant with the content was a vital stage to help with the interpretation of the data.

The interview transcripts from this study were read and re-read alongside the notes taken in the field to ensure that we were familiar with the depth and breadth of the data (Gale et al., 2013; Braun & Clarke, 2006). During this phase, we also referred regularly to the aims, objectives and research questions of our study to ensure they were linked to the data (Ritchie & Lewis, 2003; Furber, 2010). The PI read all of the transcripts and the second supervisor (RM) read all transcripts to ensure that she could actively participate in conversations around coding, emerging themes and interpretation. The key events and relationships from transcripts from each household were summarised graphically to capture household chronologies, including discrepancies in narratives between household members. These maps were used as aide-memoire during analysis.

4.8.6.4.2 Developing a coding framework

From the literature review and development of research questions, aims, and objectives, the student developed an initial *a priori* descriptive coding framework which was then discussed with the RM (Table 4 provides a basic initial framework). OpenCode 4.0 (University of Umeå, 2013) was used to code transcripts. Once agreed, the student applied this to the first few interviews, adding in new codes iteratively as these emerged from the data. RM applied the coding framework to a sub-sample of interviews; coding was then compared, and discrepancies reviewed and discussed. A final descriptive coding framework was agreed based on our *a priori* topics as well as the published literature. They were subsequently typed and presented in a table for ease of reference.

4.8.6.4.3 Indexing

The next stage, indexing, was done in two ways for this study. Ritchie et al., (2003) propose that the themes from the draft framework should be applied manually back into the transcript (raw data) to accurately portray the themes and categories which are identified in specific sections of the texts (Ritchie et al., 2003). Once the coding framework was agreed upon and applied to the data, I used the coded data alongside notes from the familiarisation process to begin to identify themes within the data, e.g. excerpts descriptively coded as "ideas about causality", and to identify more analytical themes within this, e.g. "dementia is a part of normal ageing".

I manually applied these themes and categories to specific or various sections of individual transcripts (Table 4). These emerging themes were discussed with RM who then carried out a review to ensure that the agreed upon themes and categories, per the *a priori* topics, and any emergent themes had not been missed. The subsequent process of indexing was carried out using a computer qualitative data analysis package (Ritchie et al., 2003; Furber, 2010).

Table 4: Indexing of data

Themes from coding framework	Transcript – household (HH)
Biological, Spirituality (Perceived causes)	"we think that it is part of old age…that you just have to understand and be patient with her…" [**HH AB 0075**]

4.8.6.4.4 Charting

The fourth stage of the framework involved charting (Table 5). After the data was indexed, it was summarised and reduced into categories using thematic charts (Ritchie et al., 2003; Gale et al., 2013) in a matrix. This ensured that sections of the data were distinct and manageable (Gale et al., 2013; Furber, 2010). The PhD student then examined theoretical links between different themes, e.g. the examination of the links between themes such as "dementia has a supernatural cause" and "help-seeking from traditional healers". Using Microsoft Word, the PhD student formulated the charts with extracts of the summarised texts (included direct quotes). As the themes and categories were mainly organised according to our *a priori* topics, the summaries included all collected data.

Table 5: Summary quotes located in the chart

Initial theme: Perceived causes - biological, spirituality/socio-economic			
Themes	**HH OP 0088**	**HH PP 0010**	**HH NN 0133**
Ageing	I think it's because she is getting older and older that is why changes…the way it is know that it's because she is old that is why she is behaving like that so		
Grief		When she thinks about her children who died then she becomes sad…she wants her sons to give her a befitting burial and now that they have died who will give her that befitting burial	
Bewitchment			A dog barking for a long time, came out to see why, saw fireball to burn the house saw a face in the fireball, a neighbour…wanted to confront him but from that day on could not walk or talk and knew that he was bewitched

4.8.6.4.5 Synthesising the data

Synthesising the data was the final stage of our methodological approach. Firstly, the data was charted and synthesised (Ritchie et al., 2003). This involved reviewing the data to make sense of the range and diversity of the whole dataset to give a full and detailed meaning to it (Ritchie et al., 2003; Furber, 2010; Smith & Firth, 2011). We compared the sub-themes and themes and merged several together, and left others as they were (Table 5).

Table 6: Final coding framework

Categories	Themes	Codes
SIGNS & SYMPTOMS OF ILLNESS	Symptoms associated with illness of the body	Mobility, aches and pains, stroke, blood pressure, hearing/sight
	Symptoms associated with illness of the mind	Loss of memory/forgetfulness, confusion, problems with language, getting lost/wandering, difficulty in comprehension, loss of skills, poor concentration, tearfulness, talking to oneself
PERCEIVED CAUSES OF SIGNS/SYMPTOMS ASSOCIATED WITH THE MIND	Biomedical	menopause, chronic illness (co-morbidities)
	Spiritual	Witchcraft / bewitchment,
	Psychosocial	Grief
	Ageing	Old age, ageing
HELP/HEALTH-SEEKING	Biomedical	Hospitals, Clinics, pharmacies
	Non-biomedical	Herbal, Faith based, Diviners
	None	No help sought
	Financial	Government support, family transfers, economic constraints on help-seeking
COURSE OF SIGNS/SYMPTOMS ASSOCAITED WITH THE MIND		Decline is inevitable; other conditions can be treated to maximise quality of life
CAREGIVING	Roles in care arrangements	Women as hands-on carers; men as decision-makers; men as financiers
	Experience	Personal hygiene, feeding, providing domestic support, shared responsibility (family/community)
	Economic impacts	Money for food, drugs (herbal/orthodox), indirect health costs (transportation, insurance), other crises (building repairs, others)
OLDER PERSON'S ROLE	Stigma	Not stigmatised; older people with problems of the mind as "childlike"
	Changing role	Advisory role, sedentary activities

During this stage, descriptive summaries could be incorporated to better clarify the data (Spencer et al., 2014). However, both my second supervisor (RM) and the PhD student agreed on the final theoretical framework, which is used to discuss the results in Chapter 6.

CHAPTER 5

5.0 Results: Quantitative Component

5.1 Study flowchart

Out of the 947 eligible participants living within an 18-kilometre radius, 900 were selected: 856 living within a 15-kilometre radius and 44 within a 15 and 18-kilometre radius. Overall, 761 interviews were completed, with a response rate of 84.6 %. 139 eligible participants were not interviewed (Figure 2). Those not interviewed comprised 55 (39.6%) listed but who had died by the time of the study, 35 (25.2%) had language barrier issues (although they spoke Twi, they were not fluent enough to be interviewed and undergo cognitive testing), 34 (24.5%) were considered out migrated (had moved out from their listed address for more than 3 months), 3 (2.2%) were below the age of 70 years; 3 (2.2%) were too ill to participate (severe disease with short-term high risk of death); 1 (0.7%) was a wrong identification; and lastly, 1 (0.7%) was duplicated. Only 4 (2.9%) declined to participate. Respondents and non-respondents were compared (**s**ee Table 7).

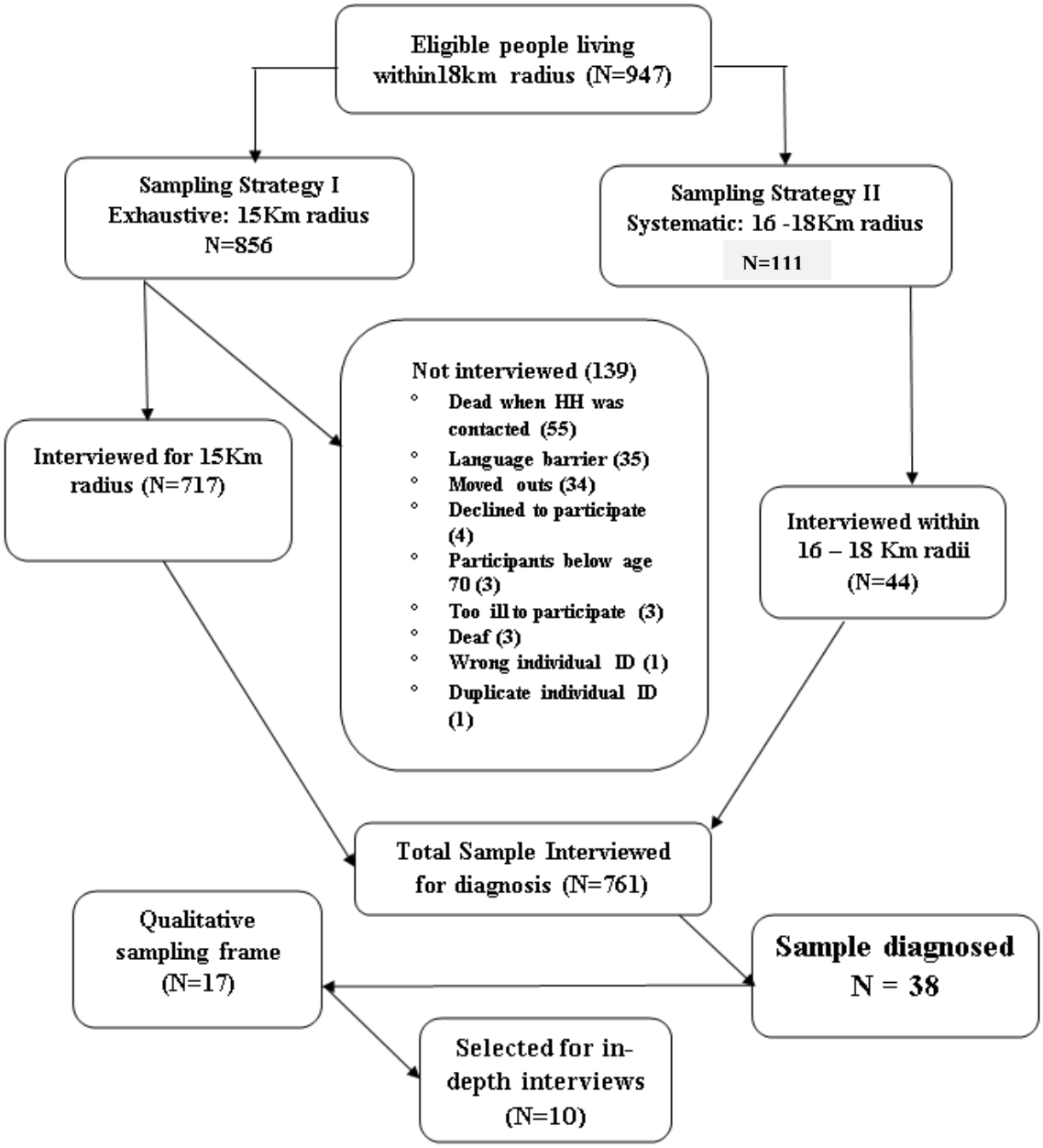

Figure 5: KHDSS population-based dementia study sampling/interview flowchart, Kintampo 2015

5.2. Comparison of respondents and non-respondents

Among those who did not respond (139), detailed information was available on 111. Hence, comparison was between 761 respondents and 111 non-respondents (Table 7). There was no statistically significant difference in the distribution of sex and marital status of respondents and non-respondents ($p>0.05$). The Welch t-test did not show a significant difference in the mean age between respondents and non-respondents ($p = 0.934$). Religious affiliations were

found to be significantly different between respondents and non-respondents based on the Fisher's exact test ($p < 0.001$).

Table 7: Comparison for demographic characteristics of respondents and non-respondents, Kintampo, 2015

Characteristics	Respondents N (%)	Non-respondents N (%)	Chi-squared	P-value
Sex			0.0069	0.934
Female	367 (48.2)	54 (48.6)		
Male	394 (51.7)	57 (51.3)		
Age in years; mean (SD)	79.71 (7.1)	80.89 (8.7)		0.1755[±]
Religion			23.1611	0.001
Agnostic / atheist	16 (2.1)	0 (0.0)		
Muslim	221 (29.1)	53 (47.7)		
Roman Catholic	133 (17.5)	22 (19.8)		
Protestant /Anglican	102 (13.4)	10 (9.0)		
Other Christian	113 (14.8)	10 (9.0)		
Jewish	35 (4.6)	0 (0.0)		
Other	140 (18.4)	16 (14.4)		
Marital status				0.163[+]
Married	408 (53.9)	52 (46.8)		
Divorced	57 (7.5)	7 (0.6)		
Widowed	279 (36.8)	52 (46.8)		
Never married	13 (1.7)	0 (0.0)		
Total	761 (100)	111 (100)		

[±]*The p-value estimate from the Welch-t-test;* [+]*P-value estimate from the Fisher's exact test; N (%) represents column percent*

It was observed that Muslims (47.7%) were more likely to refuse participation than the other religious groups. This may be attributed to perhaps the 'sensitive' nature of Muslim families to disclose private and intimate health details of an elderly family member to someone who do not share their religious faith. More so when the assessment might have seemed very probing by nature, to the IOP, key informants, and other family members present. Additionally, it might have been because the PI's gender could have contributed to non-participation among Muslim families despite proper introductions by officials from the KHRC as the lead person, who will routinely supervise/conduct interviews in all selected households.

5.3 General characteristics of respondents

Demographic, household structure, socioeconomic, social network, lifestyle and self-related health characteristics and health service use of respondents are presented in Tables 8 to 14, following.

5.3.1 Socio-demographic characteristics

Approximately 48% (n=367) of those assessed were females with a sex ratio of M: F = 1: 0.9 (Table 8). The mean age of participants was 79.71 (SD = 7.11 years), respectively 79.5 ± 6.7 in men and 79.9 ± 7.5 in women. The youngest respondents were 70 years old (per the age threshold identified for study criteria); the oldest participants were aged 115 years in men and 120 years in women. Most (n=225; 29.5%) of the respondents were in the 75-79 years age band. A relatively low proportion (1.7%) of respondents never married, however, the majority (97.6%) of participants had been married at some point in their life.

The literacy rate (reading and writing) of respondents was low, 8.3% overall. However, this information was not available for 6.6% of the participants, who refused to take the short test given by the interviewer. As none of those participants had received formal education, the literacy rate among our sample is likely to be even lower than the rate reported here.

A majority of the participants (85.0%) did not have formal education and in those who had, a significant low proportion attained tertiary level (0.5%). A significantly higher proportion of women did not have formal education (93.5% vs. 77.2%, $p<0.0001$).

Among the respondents, Christians were the largest (45.7%) religious group and Buddhists the smallest (0.2%) in this setting.

Table 8: Demographic characteristics of respondents, Kintampo, 2015

Characteristics	Respondents (n=761)	%	Male (n=394)	%	Female (n=367)	%
Sex						
Female	367	48.2				
Male	394	51.7				
Age						
70-74	185	24.3	100	25.4	85	23.1
75-79	225	29.5	117	29.7	108	29.4
80-84	179	23.5	89	22.6	90	24.5
85-89	103	13.5	56	14.2	47	12.8
90+	69	9.0	32	8.1	37	10.0
Marital status	*4**	*0.5**	*1*	*0.2*	*3*	*0.8*
Never married	13	1.7	11	2.8	2	0.5
Married / cohabiting	408	53.6	314	79.	94	25.6
Widowed	279	36.6	39	9.9	240	65.4
Divorced	57	7.5	29	7.3	28	7.6
Education						
None	647	85.0	304	77.1	343	93.4
Minimal/did not complete primary	38	5.0	26	6.6	12	3.2
Completed primary	54	7.1	44	11.1	10	2.7
Completed secondary	18	2.3	16	4.0	2	0.5
Completed tertiary	4	0.5	4	1.0	0	0
Literacy –reading	*50**	*6.5**	*27*	*6.8*	*23*	*6.2*
No	648	85.1	312	79.2	336	91.5
Yes	63	8.2	55	13.9	8	2.2
Literacy –writing	*51**	*6.7**	*27*	*6.8*	*24*	*6.5*
No	647	85.0	311	78.9	336	91.5
Yes	63	8.3	56	14.2	7	1.9
Religion	*1**	*0.1**	*0*	*0*	*1*	*0.2*
Agnostic / atheist	16	2.1	10	2.5	6	1.6
Roman Catholic	133	17.5	56	14.2	77	21.
Protestant /Anglican	102	13.4	32	8.1	70	19.0
Other Christian	113	14.8	49	12.4	64	17.4
Jewish	35	4.6	16	4.0	19	5.2
Muslim	221	29.0	127	32.2	94	25.6
Buddhist	2	0.2	2	0.5	0	0
Other	138	18.1	102	25.9	36	9.8

* = *Missing value*

A significant number (n = 571; 75.0%) of respondents were heads of their households (Table 9). Most of the older men taking part were heads of households (93.9%) whilst just over half (54.8%) of older women had this role. Living or sharing with co-residents was the norm in Kintampo: 68.8% of the respondents had co-resident(s), ranging from 1 to 10 people. However, 1.7% reported they lived with as many as 16-22 adults aged ≤16 years and another 0.8% lived with 16-25 children aged >16 years in their households (description of households and compounds in 4.4.1).

Table 9: Relationship between respondents and their household, Kintampo, 2015

Household	Respondents (n= 761)	%
Head		
Yes	571	75.0
No	190	24.9
Have children		
Yes	740	97.2
No	21	2.7
Number of co-residents		
No co-resident	20	2.6
1-3	155	20.3
4-6	210	27.6
7-9	159	20.9
10	217	28.5
Number of co-residents (adult >16 years)		
0-5	484	63.6
6-10	208	27.3
11-15	56	7.3
16+	13	1.
Number of co-residents (children <16 years)		
0-5	544	56.
6-10	117	23.2
11-15	34	4.4
16+	6	0.8

5.3.2 Socio-economic characteristics

Around a third (34.2%) of respondents occupied the 2nd quarter position for assets with a significantly high proportion (97.9%) owning their accommodation (Table 10). The majority of respondents in Kintampo indicated they did not receive benefits or income. Only a small proportion (7.5%) reported they received any income or benefits. Of these, 1.9% received government or disability pensions (not included presented in the table), 3.1% received income from family, and 0.8% received rent as an income.

Table 10: Socioeconomic characteristics of respondents, Kintampo, 2015

Characteristics	No of respondents (n= 761)	%
Position in quarters per number of assets		
1st quarter (least assets)	114	14.9
2nd quarter	260	34.2
3rd quarter	153	20.1
4th quarter (most assets)	234	30.7
Ownership of accommodation		
Owned	745	98.0
Rented	14	1.8
Missing value	***2***	***0.2***
Receive benefits/income (any)		
No	704	92.5
Yes	57	7.5
Receive income from government pension		
No	746	98.0
Yes	15	2.0
Food insecurity		
No	521	68.4
Yes	236	31.0
Missing value	***4***	***0.5***
Possess health insurance card		
Yes	650	85.4
No	109	14.3
Missing value	***2***	***0.2***

Specified amounts received ranged from GH¢30.00–GH¢500.00 (*US$7.00-116.00*) and GH¢20.00-GH¢150.00 (*US$5.00-35.00*) for government and disability pensions respectively (only for those who had worked in the government sectors) (for information - current new minimum allowed pension = GH¢296.89 per month; *US$68.28*). Income received from family was GH¢100.00 (*US$23.15*) and GH¢200.00 (*US$46.31*) for renting out accommodation. The State provides free health insurance for older people (70 year plus) in Ghana. A fee of GH 5.00 (*US$1.15*) is charged for registration. Therefore, subscription for individual health insurance coverage was high. Most (85.4 %) of respondents had health insurance cover. However, 14.3% indicated their national health insurance card had expired and re-registration was at renewal stage.

5.3.3 Social network

Overall, respondents reported they attended religious activities more regularly (45.3%) than they did for social activities (Table 11). Most of the respondents lived within a mile or in the same home with relatives (87.8%), siblings (56%), and children (87.6%). Around two thirds (57.7%) reported they had friends in the community. Respondents also reported; they had friends visiting daily (54.2%), saw neighbours daily (87.0%), and 57.3% of them said they were satisfied with the support extended from friends in the community. This reflects a general communal and cohesive relationship amongst the people in Kintampo. However, only 30.6% reported they had one close friend.

Table 11: Respondents' social network, Kintampo, 2015

Social categories	**Sample (n= 761)**	**%**	Male (n=394)	**%**	Female (n=367)	**%**
Attend social gathering						
No	416	54.66	208	52.79	208	56.68
Yes, regularly	146	34.17	86	21.83	57	15.53
Yes, occasionally	201	20.11	100	25.38	101	27.52
Missing value	***1***	***0.13***	***0***	***0***	***1***	***0.27***
Attend religious meeting						
No	214	28.12	105	26.65	109	29.70
Yes, regularly	345	45.34	171	43.40	174	47.41
Yes, occasionally	152	19.97	76	19.29	76	20.71
Missing value	***50***	***6.57***	***42***	***10.66***	***8***	***2.18***
Have friends in the community						
No	321	42.18	121	30.71	200	54.50
Yes	439	57.69	272	69.04	167	45.50
Missing value	***1***	***0.13***	***1***	***0.25***	***0***	***0***
Distance from nearest relative(s)						
Within 1 mile/same home	668	87.78	341	86.55	327	89.10
1-15 miles	67	8.81	37	9.39	30	8.17
16-50+	26	3.42	16	4.06	10	2.72
Distance from nearest sibling(s)						
No sibling	43	5.70	28	7.11	15	4.09
Within 1 mile/same home	484	63.60	242	61.42	242	65.94
1-15 miles	106	14.00	52	13.19	54	14.71
16-50+	128	16.81	72	18.28	56	15.25
Distance from nearest child						
No children	4	0.53	0	0	4	1.09
Within 1 mile/same home	667	87.65	337	85.53	330	89.92
1-15 miles	32	4.20	15	3.80	17	4.63
16-50+	34	4.47	24	6.09	10	2.72
Missing values	***24***	***3.15***	***18***	***4.57***	***6***	***1.63***

5.3.4 Lifestyle

Lifestyle-related characteristics of the participants in this study are presented in Table 12. Overall, the majority of respondents were not smoking: more than two-thirds (68.5%) had never smoked. Unlike smoking, more than half (57.3%) did not disclose whether they had been heavy alcohol drinkers, though a high proportion (79.9%) said their drinking was not harmful. As for smoking, alcohol consumption was more frequent amongst men than women.

Around three percent (2.9%) admitted their current drinking habit was harmful and had formed the habit when they were in their early 20s. A significantly high proportion (75.1%) ate fish compared to those (6.0%) who ate meat. This may be because fish was comparatively cheaper than meat in this setting. Similar proportions reported they ate fruits and vegetable in small (17.5%) or substantial (17.5%) portions in the last three days. Despite their age, almost all (93.3%) reported being, and continue to be, physically active, and 87.0% said they had walked at least 0.5 kilometres in the last month. However, most of them indicated they were not as active as a decade ago (97.1%).

Table 12: Lifestyle related characteristics of respondents, Kintampo, 2015

Characteristics	No of respondents (n= 761)	%
Smoking		
Never smoked	523	68.7
Formerly smoked	156	31.2
Current smoker	81	10.6
Alcohol		
Heavy drinker - ever		
No	228	29.9
Yes	97	12.7
Missing value	***436***	***57.3***
Hazardous drinker - now		
A hazardous drinker	22	3.0
Not a hazardous drinker	297	39.0
Missing value	***442***	***58.0***
Hazardous drinker - early adult life		
A hazardous drinker	87	11.4
Not a hazardous drinker	608	80.0
Missing value	***66***	***8.6***
Diet		
Eat meat (frequency)		
Never	17	2.2
Some days	629	82.6
Most days	66	8.6
Everyday	46	6.0
Missing value	***3***	***0.3***
Eat fish (frequency)		
Some days	83	10.9
Most days	104	13.6
Everyday	571	75.0
Missing value	***3***	***0.4***
Fruits & vegetable (servings in the last 3 days)		
0 = 0-2	133	17.5
1 = 3-4	271	35.6
2 = 5-7	216	28.4
3 = 8+	133	17.5
Missing value	***8***	***1.0***
Exercise		
Very physically active	268	35.2
Fairly physically active	442	58.1
Not very physically active	40	5.2
Not at all physically active	7	0.9
Missing value	***4***	***0.5***

**= Missing value; Alcohol intake measurement: *Pito = a local beer; *=Akpeteshie = local equivalent of rum/whisky/gin or such liquor. Alcohol intake measurement: 1 glass of beer (250 ml = 2 units), 1 jug of draught beer (750 ml = 6 units), 1 calabash of pito* / palm wine (750 = 6 units) or 1 Fanta bottle of pito / palm wine (330 ml = 2.64 units), 1 shot of liquor or Akpeteshie* (22 ml = 2 units), or 1 glass of wine or sherry (175 ml = 2 units), and 1 bottle of liquor (1000 ml = 32 units).*

Sex differences in lifestyle-related characteristics

There was a statistically significant association between sex and smoking status ($x^2 = 163.8$; p = 0.001; Table 12b). Among those who have ever smoked, 13.9% were women and 86.1%

were men. The results also showed statistically significant association between sex and alcohol intake ($x^2 = 0.7$; $p = 0.009$).

Table 12b: Lifestyle related characteristics of respondents by sex, Kintampo, 2015

Characteristics	Sex (n=761)			
	Female n (%)	Male n (%)	Chi-square	P-value
Smoking			163.7515	0.001
Never smoked	334 (63.8)	189 (36.1)		
Ever smoked (formerly/current)	33 (13.8)	205 (86.1)		
Alcohol				
Heavy drinker - ever			6.7583	0.009
No	72 (31.6)	156 (68.4)		
Yes	17 (17.5)	80 (82.4)		
Missing value	***436 (57.3)***			
Hazardous drinker - now				
A hazardous drinker	5 (22.7)	17 (77.2)		
Not a hazardous drinker	80 (26.9)	217 (73.0)	0.1856	0.667
Missing value	***442 (58.1)***			
Hazardous drinker - early adult life				
A hazardous drinker	15 (17.2)	72 (82.7)		
Not a hazardous drinker	309 (50.8)	299 (49.1)	34.4886	0.000
Missing value	***66 (8.6)***			
Diet				
Eat meat (frequency)				
Never	14 (82.3)	3 (17.6)		
Some days	299 (47.4)	331 (52.5)		
Most days	30 (45.4)	36 (54.5)		
Everyday	24 (52.1)	22 (47.8)	8.5613	0.036
Missing value	***3 (0.4)***			
Eat fish (frequency)				
Some days	41 (49.4)	42 (50.6)		
Most days	57 (54.8)	47 (45.2)		
Everyday	269 (47.0)	303 (52.9)	2.1735	0.337
Missing value	***3 (0.39)***			
Fruits & vegetable (servings in the last 3 days)				
0 = 0-2	49 (36.8)	84 (63.1)		
1 = 3-4	130 (47.9)	141 (52.0)		
2 = 5-7	118 (54.6)	98 (45.3)		
3 = 8+	67 (50.3)	66 (49.6)	10.6982	0.013
Missing value	***8 (1.0)***			
Exercise				
Very physically active	113 (42.1)	155 (57.8)		
Fairly physically active	226 (51.1)	216 (48.8)		
Not very physically active	24 (60.0)	16 (40.0)		
Not at all physically active	3 (42.8)	4 (57.1)	7.7340	0.052
Missing value	***4 (0.53)***			

5.3.5 Health

Presented in Table 13 are respondents' self-reported chronic communicable and non-communicable diseases, including comorbid illnesses. Respondents reported they suffered from 12 of the listed 15 physical illnesses. Notably, significantly high proportions reported they had not had a previous diagnosis of hypertension (82.9%) or diabetes (95.8%). There was a significantly high proportion (98.4%) who said they had never contracted TB and almost none (97.0%) had had any head injury. The self-reported nature of the data on chronic and non-communicable conditions probably explains the low rates reported in the sample for chronic conditions, for both older men and women, who can have difficulties accessing health care services. On the contrary, malaria was the most (53.2%) reported illness among them. Easier access to diagnosis and a greater awareness of this infectious disease might explain this greater rate.

A few respondents (5.2%) reported a known first-degree family member who might have had the dementia condition. However, considering that dementia is often not well identified in such settings, and that it is unlikely that a formal diagnosis was established, this can't be interpreted reliably. A low proportion (4.4%) rated their disability from bad to very bad and have been severely limited and restricted in performing daily activities in the past 30 days. Between hearing and vision impairment, those whose were severely hindered in their sight were more (6.4%) than those severely hindered with their hearing (0.9%). They generally rated their own overall health as good.

Table 13: Self-reported health of respondents, Kintampo, 2015

Self- reported health categories	No of respondents (n= 761)	%
Hypertension		
No	631	83.0
Yes	129	16.9
Missing value	***1***	***0.1***
Heart problems		
No	715	94.0
Yes	32	4.2
Missing value	***14***	***1.8***
Stroke		
No	750	98.6
Yes	9	1.2
Missing value	***2***	***0.2***
TIA (*Transient Ischemic Attack/Mini Stroke)*		
No	640	84.1
Yes	99	13.0
Missing value	***22***	***2.9***
Head injury		
No	745	97.0
Yes	19	2.5
Missing value	***4***	***0.5***
Diabetes		
No	729	95.8
Yes	31	4.0
Missing value	***1***	***0.1***
COAD; cough (*spit out phlegm when coughed)*		
No	495	65.0
Yes	265	34.8
Missing value	***1***	***0.1***
Tuberculosis; TB		
Never	749	98.4
In the last 5 years	4	0.5
More than 5 years	2	0.2
Missing value	***6***	***0.8***
Malaria		
Never	279	36.6
In the last 5 years	405	53.2
More than 5 years	73	9.6
Missing value	***4***	***0.5***
Past history of depression		
No	714	93.8
Yes	44	5.8
Missing value	***3***	***0.4***

(Continue)

Table 13: Self-reported health of respondents, Kintampo, 2015

Self- reported health categories	No of respondents (n= 761)	%
First degree family history of dementia condition		
Yes	714	93.8
No	40	5.2
Missing value	***7***	***0.9***
Pain – how often it is experienced		
Never	166	21.8
2-3 times in the month	8	17.4
Once a week	5	1.0
2-3 days a week	17	2.2
Every day	0	0
Missing value	***565***	***74.2***
Disability: in the past 30 days		
Very good	91	11.9
Good	350	46.0
Moderate	285	37.4
Bad	30	3.9
Very bad	4	0.5
Missing value	***1***	***0.1***
Visual impairment		
No problem	396	52.0
Has problem, interferes not at all	237	31.1
Has problem, interferes a little	78	10.2
Has problem, interferes a lot	49	6.4
Missing value	***1***	***0.1***
Hearing impairment		
No problem	667	87.6
Has problem, interferes not at all	62	8.1
Has problem, interferes a little	24	3.1
Has problem, interferes a lot	7	0.9
Missing values	***1***	*0.1*

5.3.6 Use of services

Few (3.9%) had seen the doctor in the last three months but some (22.1%) had been picking up medication from health facilities (Table 14). Far more (22.1%) respondents preferred to consult a doctor in the government hospital than either a private doctor (10.9%) or other government health worker (0.2%). This might be partly explained by the short distance between the main government hospital and their residence, as Kintampo main hospital is located in our study area. Similar proportions had sought traditional healers (0.9%) or been hospitalised (0.6%), and notably none of them had used the services of a dentist. However, 62.3% of the respondents said they were on medication, possibly to manage other comorbid illnesses though they did not specify how long they had been on medication.

Table 14: Respondents' use of health services, Kintampo 2015

Health service categories (used in the last 3 months)	Respondents (n= 761)	%
Government primary care		
No	731	96.0
Yes	30	4.0
Government hospital doctor		
No	593	78.0
Yes	168	22.1
Other government health worker		
No	759	99.7
Yes	2	0.3
Private doctor		
No	678	89.1
Yes	83	10.9
Traditional healer		
No	754	99.1
Yes	7	0.9
Hospitalisation		
No	756	99.3
Yes	5	0.7
Medication		
No	285	37.4
Yes	474	62.3
Missing value	***2***	***0.3***

5.4 Prevalence of probable dementia

Among the 761 respondents screened from the KHDSS, 38 were identified with probable dementia according to the short 10/66 diagnostic schedule and algorithm. Of those, 25 were females and 13 were males. The distribution of cases identified with probable dementia by age and sex is presented in Table 15.

The overall prevalence of probable dementia was estimated at 4.9 % (95% CI 3.6 – 6.8). This prevalence was higher in women (6.8 %; 95% CI: 4.7 - 10.0) than in men (3.3%; 95% CI: 1.89 -5.54). The mean age of participants with probable dementia was 84.95 years (SD=11.38 years). The youngest participant with probable dementia was 70 years old and the oldest was over 90 years. The prevalence of probable dementia increased with age, with the age-specific prevalence starting at 3.1% (95% CI 1.5 – 7.0) for 70 – 74 and increasing up to 17.4% (95% CI: 10.1 – 28.2) for those 90 years or older.

Table 15: Prevalence of probable dementia (%) by age and sex, Kintampo, 2015

Age and sex	All Respondents	Probable dementia			
	N (%)	N	Prevalence (%)	95% CI	Standardised Prevalence %*
70-74	**185 (24.3.)**	**6**	**3.2**	**1.47 - 7.02**	
Female	85 (11.2.)	4	4.7	2.00 - 12.00	
Male	100 (13.1.)	2	2.0	0.00 - 8.00	
75-79	**225 (29.6.)**	**7**	**3.1**	**1.49 - 6.40**	
Female	108 (14.2)	5	4.6	2.00 – 11.00	
Male	117 (15.4)	2	1.7	0.00 – 8.00	
80-84	**179 (23.5)**	**9**	**5.0**	**2.48 – 9.94**	
Female	90 (11.8)	6	6.6	3.00 – 14.00	
Male	89 (11.7)	3	3.3	1.00 – 10.00	
85-89	**103 (13.5)**	**4**	**3.9**	**1.49 – 9.75**	
Female	47 (6.2)	4	8.5	3.00 – 21.00	
Male	56 (7.3)	0	0.00	0.00	
90+	**69 (9.1)**	**12**	**17.4**	**10.12 -28.25**	
Female	37 (5.0)	6	16.2	7.00 -32.00	
Male	32 (4.2)	6	18.7	9.00 -36.00	
All ages	**761 (100.00)**	**38**	**5.0**	**3.65 - 6.79**	**6.6***
Female	367 (48.2)	25	6.8	4.70 - 10.03	7.3*
Male	394 (51.8)	13	3.3	1.89 - 5.54	5.7*

95% confidence intervals derived from robust standard errors, adjusted for household clustering
**Direct standardisation on overall ages, age & sex, with estimates from the UN Population Prospects 2015 as the standard population*

To facilitate comparison of prevalence estimates between Kintampo and the world, the prevalence of probable dementia for the 70 years and over was standardised on age and age-and-sex using the world population estimates as the standard population (Table 15). The standardised prevalence of probable dementia for all ages was higher (7.3 %) in females than in males (5.7 %) with an overall prevalence being 6.6 %. The standardised rates were slightly higher than the crude rates.

5.4.1 Population affected with probable dementia

The participants identified with probable dementia and those without dementia were compared using their cognitive scores (COGSCORE), informant report (RELSCORE) and depression score (Euro_D) in box and whisker plots (Figures 6-9) in order to explore the differences between the two groups.

5.4.1.1 Cognitive scores

There was a clear indication of poorer cognitive function in those identified with probable dementia. The group without probable dementia had significantly higher cognitive scores (28.6 ± 2.6) than those with probable dementia (22.7 ± 3.3), p<0.001 (Figure 6). The box and whiskers plot indicate that some people not identified with probable dementia recorded low cognitive scores (dotted image). Those participants might have had low performances with the CSI-D cognitive tests (COGSCORE) but were not rated with significant cognitive and functional impairment by their informant (RELSCORE) and / or have been identified with depression symptoms by the Euro_D scale, which would explain that they had a low probability of dementia given by the 10/66 diagnostic algorithm.

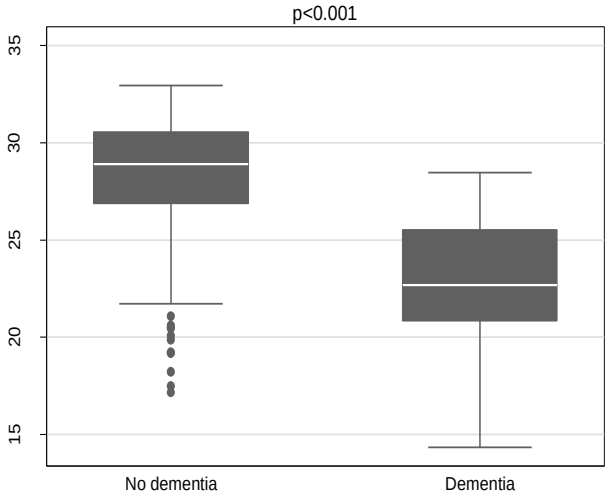

Figure 6: No probable dementia and probable dementia cognitive scores

5.4.1.2 Informants' score

Informants' reports provided evidence of cognitive and functional decline (RELSCORE) in their older relative (Figure 7). The scores for those without probable dementia was significantly lower (2.4 ± 1.2) than those with probable dementia (6.9 ± 5.3), p<0.001. This indicates a

greater decline in cognitive function and daily functioning that was perceived by the informants of participants with probable dementia (Figure 6).

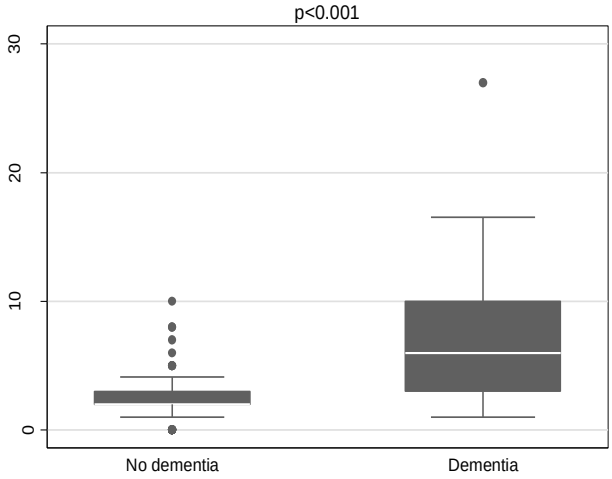

Figure 7: Informants' score for no probable dementia and with probable dementia

5.4.1.3 Depression scores

Depression scores for both groups are presented in Figure 8. Those with probable dementia had an average depression score of 3.3 ± 2.0 and those without probable dementia scored one of 2.6 ± 2.0. There was no significant difference ($p<0.05$) between both groups. However, the distribution of scores seems to differ between those two groups with scores from participants not identified with probable dementia ranging from 1 to 4 and those of participants identified with probable dementia ranging from 2 to 5. The presence of subsyndromal depression cases in our sample cannot be excluded and could explain the absence of difference regarding mean scores between our two groups. We must also acknowledge that a significant difference might be difficult to show considering the small number of participants identified with probable dementia.

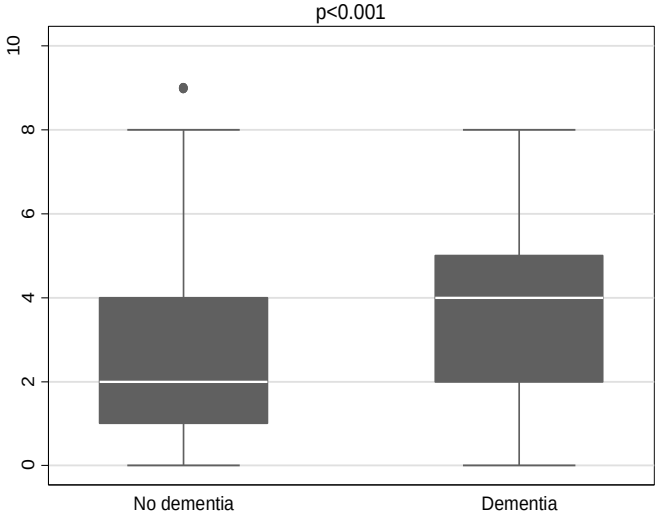

Figure 8: Depression scores for no probable dementia and with probable dementia

5.5 Associations with probable dementia

5.5.1 Demographic and socio-economic factors

Probable dementia was associated with increasing age and female sex ($p<0.05$), although the association with sex disappeared when adjusted on other factors (Table 16). The prevalence of dementia tended to be higher for older people: for those aged 75-79 years it was 1.3 times higher the prevalence of dementia for those 70-74 years (95% CI: 0.43-3.80). A non-significant trend towards a protective effect of education was observed. After adjustment, the prevalence of probable dementia among participants with no formal education was 18% higher than the one among those with some level of education. Marital status was not associated with dementia prevalence in this population.

Table 16: Association of probable dementia and demographic, socio-economic characteristics, Kintampo, 2015

Characteristics		Probable dementia			
		No dementia N= 723 (%)	Probable dementia N= 38 (%)	Crude PR* (%) 95%CI	Mutually adjusted PR (%), 95% CI
Sex					
	Female	342 (47.3)	25 (65.8)	Ref	Ref
	Male	381 (52.7)	13 (34.2)	0.48 (0.25 - 0.93)	0.88 (0.37 - 2.11)
Age					
	70-74	179 (24.8)	6 (15.8)	Ref	Ref
	75-79	218 (30.1)	7 (18.4)	0.96 (0.33 - 2.81)	0.92 (0.33 - 2.61)
	80-84	170 (23.5)	9 (23.7)	1.55 (0.56 - 4.27)	1.30 (0.43 - 3.80)
	85-89	99 (13.7)	4 (10.5)	1.21 (0.35 - 4.15)	1.14 (0.31 - 4.12)
	90+	57 (7.9)	12 (31.6)	5.36 (2.10 - 13.74)	2.91 (0.98 - 9.50)
Education					
	None	613 (85.0)	34 (89.5)	Ref	Ref
	Some level of education	110 (15.20)	4 (10.5)	0.67 (0.24 - 1.88)	0.82 (0.27 - 2.47)
Marital status (MV= 4)					
	Never married	12 (1.7)	1 (2.6)	Ref	Ref
	Married / cohabiting	395 (54.6)	13 (34.2)	0.41 (0.06 - 2.94)	0.77 (0.61 - 9.97)
	Widowed	257 (35.5)	22 (57.9)	1.03 (0.15 - 7.04)	1.31 (0.12 - 13.42)
	Divorced	55 (7.6)	2 (5.2)	0.46 (0.05 - 4.67)	0.81 (0.51 - 14.02)
Respondent is head of house		548 (75.8)	23 (60.5)	0.51 (0.27 - 0.96)	0.54 (0.26 - 1.14)
Socioeconomic position					
	Number of assets				
	1 (least assets)	109 (15.1)	5 (13.1)	Ref	Ref
	2	244 (33.7)	16 (42.1)	1.40 (0.52 - 3.74)	1.43 (0.51 - 4.11)
	3	147 (20.3)	6 (15.8)	0.89 (0.28 - 2.86)	0.84 (0.30 - 2.61)
	4 (most assets)	223 (30.8)	11 (28.9)	1.07 (0.38 - 3.01)	1.10 (0.35 - 2.90)
Self-rated health in past 30 days (MV= 1)					
	Very good	87 (12.0)	4 (10.8)	Ref	Ref
	Good	335 (46.0)	15 (40.5)	0.98 (0.33 - 2.87)	0.71 (0.21 - 2.30)
	Moderate	272 (37.6)	13 (35.1)	1.04 (0.35 - 3.11)	0.71 (0.22 - 2.31)
	Bad	26 (3.6)	4 (10.8)	3.03 (0.81 - 11.40)	1.20 (0.26 - 5.23)
	Very bad	3 (0.4)	1 (2.7)	5. 69 (0.81 - 40.10)	0.40 (0.45 - 3.03)
Care needs					
	Needs care much of the time	4 (0.5)	4 (10.5)	Ref	Ref
	Needs care some of the time	7 (1.0)	4 (10.5)	0.73 (0.25 - 2.07)	1.02 (0.24 - 4.31)
	Does not need care	712 (98.5)	30 (78.9)	0.08 (0.04 - 0.18)	0.20 (0.44 - 0.70)

**PR=Prevalence Ratios; 95% CI derived from robust and mutually adjusted for all other covariates in the model; SRH=Self-reported health*

5.5.2 Lifestyle and health-related factors in Kintampo

There was a significant association of probable dementia with only one of the lifestyle and health related variables (Table 17). Participants with probable dementia were significantly more likely to report a poorer physical activity (p=0.001). The prevalence of dementia among those who had walked less than 0.5 km in the last month was 2.5 times higher than those who had not walked the same distance (95% CI: 1.23-5.34, p= 0.009). There was no significant

difference in lifetime smoking in those with and without probable dementia, and diet did not seem to be associated with probable dementia in this setting either.

Table 17: Dementia and lifestyle and health-related factors, Kintampo, 2015

Characteristics	No dementia n= 723 (%)	Probable dementia N=38	PR	95% CI	P-value
Lifestyle					
Smoking					
Never	494 (68.33)	29 (76.32)	Ref	Ref	
Current smoker	75 (10.4)	6 (15.8)	0.35	0.11-1.13	
Former smoker	153 (21.2)	3 (7.9)	1.33	0.58-3.09	0.208
Diet					
Eating meat					
Never	15 (2.1)	2 (5.3)	Ref	Ref	
Some days	603 (83.4)	27 (71.0)	1.13	0.17- 7.80	
Most days	63 (8.7)	3 (7.9)	1.50	0.15-13.70	
Every day	42 (5.8)	4 (10.5)	1.70	0.20-13.83	0.8579
Eating fish					
Some days	78 (10.8)	5 (13.2)	Ref	Ref	
Most days	101 (13.9)	3 (7.9)	0.63	0.15- 2.70	
Everyday	544 (75.2)	28 (73.7)	1.02	0.40- 2.91	0.7246
Exercise					
Walk > 0.5 km in past month					
Yes	637 (88.1)	25 (65.8)	Ref	Ref	
No	84 (11.6)	11 (28.9)	2.50	1.23- 5.34	0.009
Health - *SRH					
Diabetes					
No	693 (95.8)	36 (94.7)	Ref	Ref	
Yes	30 (4.1)	1 (2.6)	0.60	0 .11- 4.80	0.632
Family history of dementia					
No	681 (94.1)	33 (86.8)	Ref	Ref	
Yes	37 (5.1)	3 (7.9)	1.60	1.03- 4.60	0.426
Head injury					
No	704 (97.4)	35 (92.1)	Ref	Ref	
Yes	17 (2.3)	2 (5.26)	2.0	0.41- 8.03	0.428
TIA					
No	610 (84.4)	30 (78.9)	Ref	Ref	
Yes	93 (13.0)	16 (15.8)	1.30	0.54- 3.13	0.558

**SRH = Self-reported health; PR: Adjusted household clustering prevalence ratios*

5.5.3 Social interactions

For the elderly in Kintampo, dementia was observed to be associated with poorer social interactions measured by their attendance to religious meetings (Table 18). Comparably, those with probable dementia were less likely to attend any social gathering (funerals, outdooring/child naming ceremonies, community gathering) than those without probable

dementia. Those with probable dementia were 2.8 times less likely to attend religious meetings than those who occasionally attended (95% CI: 0.94-8.54, p=0.0008). There was no significant difference between those who reported they had friends and had no friends in the community (p=0.0549).

Table 18: Association between probable dementia and social interaction

	No dementia	Probable Dementia	PR	95%CI	P-value
	N=723 (%)	N=38 (%)			
Attended meetings/social groups (MV=1)					
No	386 (53.4)	30 (78.9)	Ref	Ref	0.1437
Yes, regularly	140 (19.4)	3 (7.9)	0.51	0.15- 1.69	
Yes, occasionally	196 (27.1)	5 (13.2)	0.47	0.17- 1.30	
Attend religious meetings (MV=50)					
Yes occasionally	148 (20.5)	4 (10.5)	Ref	Ref	0.0008***
Yes, regularly	337 (46.6)	8 (21.0)	0.26	0.12- 0.58	
No	188 (26.0)	26 (68.4)	2.83	0.94- 1.54	
Friends in the community (MV=1)					
Yes	424 (58.6)	15 (39.5)	Ref	Ref	0.0549
No	298 (41.2)	23 (60.5)	0.54	0.11- 0.27	

**P<0.05, **p<0.01, ***p<0.001; PR: Adjusted on household clustering prevalence ratios*

5.5.4. Disability, needs for care and associations

5.5.4.1 Disability

For the disability scores (Figure 8), it is observed that those with probable dementia had more disability than those without probable dementia. Those without probable dementia scored lower (10.0± 11.3) compared with the probable dementia group (27.2 ± 24.1) (p<0.001), supporting the fact that dementia is a disabling condition for older people.

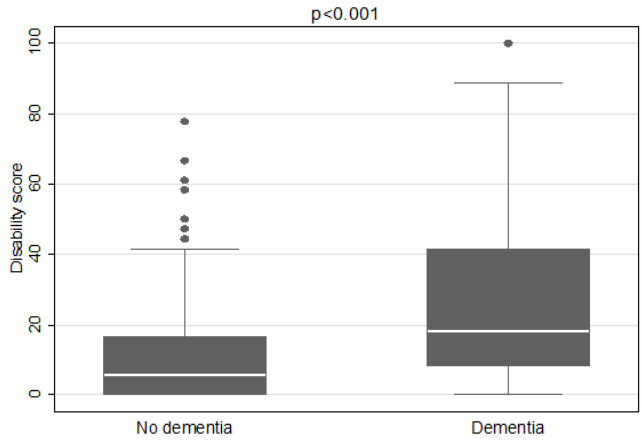

Figure 9: Disability scores for probable dementia and no probable dementia

Additionally, I investigated the effect of dementia on WHO-DAS scores (Table 19). There was a statistically significant difference in the mean disability score between those with probable dementia and those without probable dementia (p<0.001), confirming that those with probable dementia were more disabled than those without probable dementia.

Table 19: Disability and association with probable dementia, Kintampo, 2015

	Disability (whodas12)		
	Mean ± SD	**t-test statistic**	**P-value**
No probable dementia	10.00 ± 11.34	-8.4	<0.001
Probable dementia	27.19 ± 24.08		<0.001
No probable dementia#	13.89 ± 11.16	-7.1	<0.001
Probable dementia#	28.70 ± 23.84		<0.001

Omitting zeros in the whodas12 scores

The multi-variable zero-inflated negative binomial model in Table 19 shows that adjusted on a range of impairments, the prevalence of disability for those with probable dementia is approximately 1.7 times higher than the prevalence of those with no probable dementia (95% CI: 1.35 – 2.13).

Table 20: Disability and association with probable dementia, Kintampo, 2015

Self-reported impairment	Disability (whodas12)		
Variables	**PR**	**95% CI**	**P-value**
Dementia			
Negative	ref	1.35 - 2.13	<0.001
Positive	1.69		
Age in years	1.03	1.02 - 1.04	<0.001
Sex			
Female	ref		<0.001
Male	0.82	0.72 - 0.94	
Education			
some, did not complete primary	0.98	0.74 - 1.29	
completed primary	0.94	0.70 - 1.27	
completed secondary	0.67	0.48 - 0.94	
tertiary (college)	0.78	0.55 - 1.10	
Arthritis/rheumatism			
has problem, interferes not at all	1.11	0.88 - 1.40	
has problem, interferes a little	1.51	1.10 - 2.10	
has problem, interferes a lot	1.36	0.87 - 2.13	
Eyesight			
has problem, interferes not at all	1.11	0.96 - 1.28	
has problem, interferes a little	1.40	1.16 - 1.67	
has problem, interferes a lot	1.49	1.18 - 1.87	
Hearing difficulty/deafness			
has problem, interferes not at all	0.97	0.74 - 1.27	
has problem, interferes a little	1.03	0.74 - 1.44	
has problem, interferes a lot	1.18	0.82 - 1.68	
Persistent cough			
has problem, interferes not at all	1.21	1.05 - 1.39	
has problem, interferes a little	1.11	0.86 - 1.45	
has problem, interferes a lot	1.01	0.65 - 1.56	
Breathlessness/asthma			
has problem, interferes not at all	0.72	0.41 - 1.28	
has problem, interferes a little	2.40	1.10 - 5.23	
has problem, interferes a lot	1.64	1.05 - 2.64	
High blood pressure			
has problem, interferes not at all	1.22	0.95 - 1.56	
has problem, interferes a little	1.39	1.11 - 1.74	
has problem, interferes a lot	1.67	1.08 - 2.57	
Heart trouble/angina			
has problem, interferes not at all	1.04	0.75 - 1.46	
has problem, interferes a little	1.11	0.85 - 1.46	
has problem, interferes a lot	1.37	0.91 - 2.10	
Gut-(stomach/intestinal)			
has problem, interferes not at all	0.92	0.77 - 1.09	
has problem, interferes a little	1.20	0.78 - 1.85	
has problem, interferes a lot	1.24	0.78 - 1.99	
Faints/blackouts			
has problem, interferes not at all	1.02	0.76 - 1.37	
has problem, interferes a little	1.71	1.22 - 2.40	
has problem, interferes a lot	2.34	1.44 - 2.92	

PR: Prevalence Ratio; CI: Confidence Interval

5.5.4.2 Care needs

Care needs, rated for both groups, (Table 21) showed that among those with no probable dementia, 0.6% reported they needed care much of the time, while 10.53% indicated that they needed care much of the time among those with probable dementia. In both groups, needs for care were not frequently reported. This might be due to the fact that, traditionally, older people are cared for by their relatives and care beyond the usual was not commonly identified by the informants during the interview. Therefore, care needs described below will refer to care that is beyond what is usually provided by the relatives of older people, which could be seen as extra-care.

Table 21: Care needs of respondents, Kintampo 2015

10/66 short dementia	Needs for care		
	Needs care much of the time; n (%)	Needs care some of the time; n (%)	Does not need care; they are able to n (%)
No probable dementia	4 (0.5)	7 (0.9)	712 (98.5)
Probable dementia	4 (10.5)	4 (10.5)	30 (78.9)
Total	8 (1.1)	11 (1.4)	742 (97.5)

N (%): Frequency and row percentage

5.6 Care arrangements and strain

5.6.1 Care arrangements

Care arrangements were assessed for the person living with probable dementia regarding those who cared, what factors influenced division of care, how care-related decisions were made, what were the effects on carers, and what were the needs for care. Overall, very few informants (2.5%) reported their older relative needed care (ie. beyond what is usually provided by the relatives of older people) in Kintampo. For those with dementia, 21.0% reported needing care, with one or more family members, (nuclear or extended family members) providing hands on care. They reported that 2.6% of caregivers left their current job in order to care, 7.9% of carers reduced their working hours to care and the majority (n=5) carers had not cut back work to care.

Caregivers in this setting were family members and were not paid to provide care during the day and night. Paid caregivers were, therefore, non-existent. The time taken to assist their older relatives was also reported with one caregiver stating it took less than an hour to assist with transportation. Among those giving care, 50.0% said they assisted their elderly relatives to: dress (30.0%) and eat (20.0%). The other 50.0% said their elderly relative needed to be "supervised"; in the sense that the carers kept an eye on the person and ensured their safety.

5.6.2 Caregiver strain

Out of the whole sample, only 19 (2.5%) respondents completed a ZBI (Zarit Burden Interview) as a result of the low proportion of people reporting as needing extra-care. Using the Welch t-test to assess the extent to which carer strain was associated with probable dementia (Table 22), it showed there was no statistically significant difference in the mean (Zarit burden score) between carers of those with probable dementia and those without (n=19, t=0.23, p=0.820). These results should be interpreted with caution considering the low number of participants.

Table 22: Comparing mean carer strain for dementia and no dementia, Kintampo, 2015

Exposure	Observation (N)	Mean score	SD	P-value
Dementia	8	12.50	5.37	
No dementia	11	13.36	10.42	0.8200

P-value estimates from Welch t-test

5.6.3 Informant psychological morbidity

The mental health of the informant interviewed alongside the older people was examined using the self-reported questionnaire (SRQ). A total of 760 (1 missing value) responded, 675 (88.7%) did not have mental health issues and 86 (11.3%) had psychological morbidities, with a SRQ mean score of 3.38 ±0.11 (Table 23). However, there was not enough statistical evidence to conclude that being an informant of a person living with dementia had any effect (PR=1.12,

95%CI: 0.48 – 2.62) on their mental health, controlling for other variables such as age, sex, education and disability.

Table 23: Association of probable dementia and informant mental ill health

Carer SRQ	**Dementia**	
	PR	**95% CI**
Age in years		
70 - 74	ref	
75 - 79	0.91	0.32 – 2.60
80+	1.21	0.50 – 3.01
Sex		
Female	ref	
Male	0.64	0.23 – 1.25
Psychological morbidity	1.12	0.48 – 2.62

SRQ: Self-Reported Questionnaire; PR: Prevalence Ratio; ref: reference category

CHAPTER 6

6.0 Results: Qualitative Component

The results of the qualitative component are reported in this chapter. It is organised around the emergent themes from the narratives of participants. These themes were integrated in the a priori topics of interest. The chapter is divided into eight sections. Section one describes the characteristics of participants. Sections two to eight are formed around the emerged themes. These themes are: families characterisation of and or experience of dementia, beliefs about causality, views of the course of illness, help seeking behaviours, care arrangements, decision-making about the care of older persons, stigma, and other arising themes.

6.1 Characteristics of the participants (cases)

A total of 28 in-depth interviews were conducted within 10 households (cases) comprising a majority (60 %) of women and some (40 %) living with probable dementia, their caregivers and families. Most of the primary (hands-on) caregivers were females and included spouses for the male index older persons, who were themselves older persons. Only one male was a hands-on caregiver, a grandson. Three IOPs had sons-in-law or daughters-in-law living either in the same household or nearby to assist with the more strenuous tasks. Others also had some tenants providing care support. Three of the women IOPs, were strong enough to carry out basic and personal care activities such as bathing and dressing and washing clothes. Their ages ranged from 73 to 100 years old, with the youngest and oldest being men. Presented in table 24 are detail characteristics of IOPs living with dementia and their household members. Additionally, Appendix O provides summaries of interviews of all the households.

Table 24: Characteristics of older participants with dementia and their households

Household Id	Sex	Age	No. of co-residents	Caregiver/s (hands-on, financial, support)	Household structure & arrangements
AS 0552	M	85	7	Spouse, son, & older grandson (resident elsewhere)	Spouse, children & grandchildren
NN 0133	M	100	10	Spouse, & eldest son	Spouse, sons, nieces & other relatives
NN 0081	M	90	7	All residents	Spouse, daughter-in-law, & grandchildren
AS 0533	M	73	2	Spouse & son (resident elsewhere)	Spouse and tenant
OP 0088	F	85	10	*Self (support), daughter & grandchildren	Daughters, grandchildren & great grandchildren
BB 0731	F	85	6	Daughter & granddaughter	Granddaughters & other tenants
PP 0010	F	77	9	Daughter & granddaughters	Daughters & grandchildren
AB 0075	F	80	6	Grandson	Daughter-in-law & grandsons
AS 0815	F	82	8	*Self (support), daughter-in-law & grand child	Son, daughter-in-law & grandchildren
BN 0089	F	92	10	*Self (support), daughter & grandchildren	Daughter & grandchildren

**Self = that they are able to perform basic daily activities and support their care*

6.2 How the condition is experienced and or characterised

6.2.1 Symptoms associated with the decline of the mind

Overall, families understood the cognitive symptoms from the way the behaviour of their older relatives had changed over the years they had known them. Participants could not differentiate between behaviour symptoms that were due to normal ageing and those due to a pathological state, for e.g. dementia. Caregivers from all the 10 households reported their older relative experience forgetfulness or memory loss in several ways. For example, they forgot people they had known for several years, words or objects, what they were talking about or statements, where personal or household items were kept and how to perform some skills.

> *"…the people living here at Asantekwa, she knows very well and has known them for years will pass by the house…greet her and she does not recognize them…she has forgotten them…unless they mention their names". [HH AS 0185; Daughter-in-law of IOP]*

> *"It is as if she has not heard what I have been saying or said at all…she has forgotten what we were talking about…she forgets things because she is very old…that is why…all old people forget things. She can put something down and forget where she put it…she forgets things too much…she does all the time…" [HH AB 0075; Grandson of IOP]*

> *"…something he has done all his life…now if someone does not help he cannot do it…he has forgotten the steps…paused…he has forgotten how to wear his tunic…just look at him now…he has turned it backwards…" [HH NN 0081, Wife of IOP]*

Caregivers from two households also reported changes in behaviour with regards to getting lost, wandering, and sleeplessness. Older relatives were prone to leaving the house and going out of their compounds or rooms and not finding their way back. This either happened during the day, when caregivers were not vigilant, or at night when they might have dozed off and the older relatives are still awake from sleeplessness. Though this was worrisome to family members, they seemingly coped, as neighbours and/or community members inevitably found the wanderers and often led them home. They stated that:

> *"…if he goes out, he can't find his way back home which is of a great worry." [Sighs]…then we have to go and search for him…other than that he will just be walking"…until someone who knows him brings him home…" […] "What is worrying is that he doesn't sleep at night so we also don't sleep […] "you do not see him going out…bring him back home when they see him outside at night..." [HH NN 0081, Daughter-in-law and Wife of IOP respectively]*

> *"I just remembered, hmm… at times Papa can go somewhere and someone will have to bring him back to the house…my father could not sit at one place like now that you came he will not be in the house…given some herbs that we pass through his nostrils every night when he is going to sleep. It was supposed to help him to sleep and also to prevent him from roaming around." [HH AS 0533, Son of IOP]*

Other cognitive symptoms that families reported included difficulties in holding a conversation with their older relatives and other perceived emotional behaviour. Families from seven households described ways in which index older persons conversed. For instance, they had difficulties concentrating, being attentive and veered off conversations; their contributions to conversations were or seemed either illogical or unrelated.

> *"…there are changes in the way she speaks and when you are talking to her you can see that she easily goes off what we are talking about…it is only when you take your time to explain to her what you were talking about before she will come to her right frame of mind to continue the conversation." [HH NN AS 0815, Son of IOP]*

"Often, when you are talking about an issue with her, all of a sudden she will change the topic…you will struggle and struggle before you can converse with her…when you say this then she will divert it to something else…you cannot make sense of what she is saying". [HH BB 0731, Daughter of IOP]

Statements were made about the concentration of the index older person.

"I can converse with her but sometimes she loses concentration and it is as if she has not heard what I have been saying or said at all…" [HH AB 0075; Grandson of IOP]

A caregiver mentioned that their older relative sometimes conducted themselves inappropriately:

"*When Maame gave birth to us she used to talk to us nicely but now she has changed […] fights with her grandchildren often so I told them they should exercise patience with her" [HH BN 0089; Daughter of IOP]*

"I talk a lot because I am mad" […]"…she doesn't care whether there is a visitor or not…she can insult and disgrace you". [HH OP 0088; IOP and Granddaughter]

The families mentioned tearfulness, and social withdrawal as a result of cognitive impairment among older relatives.

"When I converse with him I notice that a lot has changed…at times when you are talking to him he will be crying and at times too…" [HH AS 0533; Son of IOP]

"When her children died she often thinks a lot…she will be quite for a long time…there are times when you are talking to her, her mind will not be there though she will be looking at you…you will talk and talk before she will ask whether you are talking to her…then she will sigh heavily…she was not like that". [HH BN 0089; Daughter of IOP]

A caregiver reported that her older relative sometimes wrongfully accused family members of stealing their items or money. She said:

"At times she will hide her money and later accuse the children for stealing it and when she finds it she will not say she has found it OO…all laugh…they sometimes fight with her on that…" "It happens almost every day…when she

cannot find something she has kept somewhere she accuses us of stealing it. And when she finds it she will not even tell anyone…she keeps quiet" [HH BB 0731; Daughter and Granddaughter of IOP]

6.2.2 Co-morbid physical health problems

Several physical health problems that co-existed with cognitive symptoms were mentioned. Caregivers described a general weakness of their older relatives. Families and older persons alike listed this co-morbid physical health. Three families mentioned mobility as a key weakness of the older person. They remarked:

"At first she was able to go to farm and gather firewood…she was very strong. Now she cannot even come out of her room not to even talk of going to the farm to gather firewood…she cannot walk" [HH BB 0731; Daughter of IOP]

"Because of her leg problem, she cannot even go close to fire or walk to the village…if she needs something I have to get it for her and have to be around to help her…she can do a lot of things with her hands when she is sitting…it is just her leg problem, she cannot move around well". [HH AB 0075; Grandson of IOP]

"My father could not sit at one place…like now that you came, he will not be in the house…he is old and cannot walk…long distance to the farm…" [HH AS 0533; Son of IOP]

Another three caregivers reported that, for their individual older relative, joint aches and body pains were a constant occurrence. For example:

"She complains her knee and her waist were paining her and the doctor gave her medication for those pains…" [HH BB 0731; Daughter of IOP]

"…he is not suffering from any mental illness, it is usually the pains and aches complaints Grandpa has that we often talk about when we go to the hospital. [HH AS 0552; Grandson of IOP]

"As I said…because he complains of the stomach ache, pains in his knees or if he has body pains… then they will give him medicine for the ailments…" [HH NN 0081; Wife of IOP]

Two families said individually that a stroke and blood pressure were the physical health problems their older relative suffered from.

"I think it is a stroke…I don't believe what he is saying…the way the condition looks...it is like stroke." [HH NN 0133; Son of IOP]

"They told us the first time we went that he has high blood pressure and he was given medication…the doctor told him to stop taking alcohol and salt which he stopped." [HH AS 0533; Son of IOP]

However, one index older person insisted that her symptoms were sight-related and not cognitive decline. She remarked:

"If he is passing by and I ask that who is passing, it is because I cannot see…but not that I have forgotten him…if I do not see them when I hear their voice that is when I am able to recognize them…I have a problem with my eyes" [HH AS 0815; IOP]

One caregiver reported her grandmother's hearing impairment as a problem. She stated:

"I think she has a hearing problem…at times she can hear some of the things you say but at times too she cannot hear at all…[HH BB 0731, Granddaughter of IOP]

6.3 Beliefs about causality

In their narrations on beliefs and what causes the condition, ageing, grief and witchcraft were mentioned as the cause of the condition.

6.3.1 Ageing

The extent to which a particular problem was attributable to a physical health problem, such as loss of vision, stroke, or perceived to be symptomatic of "ageing" above and beyond physical illness, was often unclear to both the younger and older participants:

"If he is passing by and I ask that who is passing, it is because I cannot see but not that I have forgotten him. It is only when they speak and when I hear their voice that is when I am able to recognize them…all what is happening is because I am very old now…when the person is passing by I will not see him or her but when they talk I can recognize them by their voice. There are times too I see them and recognize them. But if I do not see you then unless they tell me that you are passing and immediately you speak I can recognize you… it is not that I have a problem with my eyes…it is because I have grown very old that is why I have that problem with my eyesight…it is ageing." [HH AS 0815; IOP].

When asked, participants stated that they had no specific word for this condition or someone experiencing these kinds of symptoms. Nevertheless, they recognised or mentioned "old

woman's or old man's disease" in one of their dialect and in the language of interview stated by one caregiver: '***Hangyena'/'Bangyena' 'weela',*** in Mo language, and ***'Abrewa'/'Akokra' 'yariɛ'*** [HH AS 0815; Son of IOP], in Twi, as the condition which appeared to represent quite a number of dementia symptoms.

None of our participants used the term "dementia". However, there was an understanding that, over time, the human body degenerates and there is a decline in its functions. This is similar to the wear and tear seen in objects or decay witnessed in other natural things, which are seen as inevitable or fate. If one lived and grew older then there is the likelihood to experience all problems with ageing. They said:

> *"Everyone and their destiny…if your destiny is that when you grow old this is what will happen then it will happen but if it is not like that then you will be free" [HH AS 0815; IOP]*
>
> *"If there is a leaf which is very green and now it had turned yellow, you now start thinking 'when will this leaf fall down'…we sometimes think…what will happen…but God alone knows the end" [HH NN 0081; Wife of IOP]*

One caregiver of an older lady (her grand-son) clearly related her problems to a deterioration of the brain over time:

> *"You know when you buy something new and you use it for a long time it becomes old…it does not remain like you bought it. I think that is how the human brain is…when you are young it works well but when you grow old it does not work well…so when someone becomes old then every part of the body too becomes old" [HH AB 0075; Grandson to IOP]*

Observing the daily decline of the human body and viewing this over the passage of time as a cause of deterioration were mutually reinforcing. Where the worsening symptoms supported the idea of "ageing", ageing brought about observed decline and weakening of its functions. This was seen to be natural and synonymous with inevitability, thus with only one clear end point; the death of the older person:

"I think this is because he is very old now that is why it is like that…there is no way his condition will improve…I think it will be worse as he ages more…[sighs & smiles]" [HH NN 0081; Daughter-in-law of IOP]

"If she was very young and this thing started, then maybe it will stop…but considering her age now there is no way it will stop…I believe it will get worse." "I also think the same way, as she becomes older she cannot change for the better, considering her age now we know that the way she talks will change…I am not saying that she will die…but I think she is closer to her death…that is what I think." [HH AS 0815; Son & Daughter-in-law of IOP]

"Hmm…yes…you see your brain will not work as it used to work when you are in young …you know when you buy something new and you use it for a long time it becomes old…it does not remain new like you bought it. I think that is how the human brain is…when you are young it works well but when you grow old it does not work well…so when someone becomes old then every part of the body too becomes old." [HH AB 0075, Grandson of IOP]

6.3.2 Grief

For three of our participants; two caregivers of different index older persons and one index older person, grief was a precursor of the onset of cognitive symptoms. The belief that one's children ought to live to an old age to give befitting burials to their aged parents and not the other way round was not the case for these three older persons. The effect of such deaths of nuclear family members could be multi-dimensional; for example: financial losses, loneliness, etc., which could bring increased hardships. More so, when death suddenly claims not a single adult child, but two or more siblings considered either to be the main breadwinners of the family, or who might have left behind several children without adequate provisions for their upkeep. They remarked:

[Sighs audibly] "…yes…one of our brothers…passed away suddenly...he was the main breadwinner of this family…when my mum heard of it she collapsed…and was admitted in the hospital. Then not long after the one who comes after him…also passed away…" [HH OP 0088; Daughter of IOP]

"I think what makes my mother…this way is that when she thinks about her children who died then she becomes worried…that is where it all started…because she always said that she wants her sons to give her a befitting burial and now that they have died who will give her that befitting burial…fully grown men…so when Maame thinks about all these happenings then she is worried. [HH PP 0010; Daughter of IOP]

"It is not because I am ageing that is why I am behaving this way…if you have eight children and four of them suddenly die…now you only have four of them what will you do? Hmmm…I am well…what can I say…my children who should live so that when I die they bury me are dying…when the one at Kintampo died he left nine children…one of these children passed away and the one who died here also left nine children and they are all here. How to send all these children to school is what makes me think a lot. I must tell you I think a lot…" [HH BN 0089; IOP]

6.3.3 Menopause

One caregiver attributed the onset of symptoms to the time of her mother-in-law's menopause and remarked:

"Me, I think when her menopause started…that is where it all started…I used to visit my husband here and she had come to live here…it was the boy, the one who moved out, who told us what was happening with her when he came to visit us…when she was menstruating it was not there but when her menopause started that is when it also started." [HH AS 0815; Daughter-in-law of IOP]

6.3.4 Witchcraft/unnatural forces

Unlike the majority of the study participants, who saw possible symptoms of cognitive impairment as a part of "ageing", two of the families believed that supernatural forces were the primary cause of the cognitive symptoms of the older person. One participant, an older index person, narrated an incident that precipitated his condition (being unable to walk and talk) and alluded that a neighbour had caused it. For the other participant (a caregiver of older person), he believed the cognitive symptoms observed in his father were caused by the refusal to be possessed by dwarves to become the human medium for deity. They explained:

"…the doctor told me that there was nothing wrong with me…there was a time in the night that I heard a dog barking for a long time…and I came out to see why the dog would not stop howling. To my surprise I saw something…a huge fireball, so bright…I saw a face in the fireball, a neighbour, he lives in the nearby house…in the morning I wanted to confront him but from that day on I could not walk or talk and knew that he had bewitched me…" [HH NN 0133; IOP]

"I just remembered…hmmm…there are some things in this household that he cannot lift but I noticed that sometimes he will be filled with some powers and lift those things like some easy thing…sometimes too he will run and climb very

tall trees…I realized that something was wrong with him…I contacted my uncle at Baniantwe and he said that at first dwarves wanted to possess him and he did not like it, so that is why he sometimes behaves like that…for me I realized it was the devil's disease I started looking for help early… [HH AS 0533; Son of IOP]

6.4 Views of the course of the illness

Overall, it was generally acknowledged that improvements in symptoms of sickness of older relatives (including those perceived to have a supernatural cause) might be only partial and that it might not be possible to halt the progression of a natural decline. In general, families aimed and treated what they could, in order to see an improvement in the level of comfort of their older relatives:

"No…no…I don't believe it will improve…it will get worse…but maybe if we get medicine for her she might feel okay" [HH AB 0075; Grandson of IOP]

"I think all these…because …it is the fact that she is very old now". "As for us, we think it is old age so we took her to the hospital three times and stopped". [HH BB 0089; Daughter & granddaughter of IOP]

6.5 Help / health seeking behaviours

6.5.1 Biomedical services

Caregivers reported that all the qualitative sampled older persons had used western style medicine (WSM) in pharmacies, hospitals and healthcare centres since they began to exhibit their cognitive symptoms. What is interesting is their reason for using the WSM. They mainly used WSM for physical complaints and not for their cognitive symptoms. They hardly reported cognitive symptoms to WSM health workers because they considered the cognitive symptoms to be part of the general decline in health associated with ageing.

"As I said before we took him because he complains of the stomach ache, pains in his knees or if he has body pains…that is what we go and talk to health workers…then they will give his medicine for the ailments…we have never reported his behaviour to the doctor…we think its old age…it is not sickness so that is why we did not tell the doctor" [HH NN 0081; Wife of IOP]

"She said that the doctor asked Maame what was wrong with her and she said her knee and her waist were paining her and the doctor gave her medication for those pains…" [HH BB 0731; Daughter of IOP]

When asked, one caregiver reported he mentioned to the healthcare worker the problems their father was having with reasoning and conversation when they visited the hospital. The health worker diagnosed high blood pressure, provided medication for this and advised that alcohol and salt were cut from his diet. The cognitive problems were not directly addressed, and the family observed no improvements in these symptoms:

> *"They told us the first time we went that he has high blood pressure and he was given medication…the doctor told him to stop taking alcohol and salt which he stopped. After that we have gone to the hospital four times…we went there four times and stopped" …" the other things that he does that…he is behaving like a child…that one I have not seen any improvement…I told him [health worker] that my father talks and behaves like a child...but he did not talk to us about that" [HH AS 0533; Son of IOP]*

In fact, it was rare for the older person or their family members to receive a diagnosis for any of the problems presented to the healthcare worker. More commonly, they were provided with medication without any additional advice or information. In which case, families generally evaluated the impact of the treatment, leading to judgements about the nature of the problem and future actions. For example, if medication was perceived to be ineffective, it might be concluded that further visits to the same service were unlikely to be worthwhile. Lack of improvement in response to medication might be seen as evidence that symptoms were due to "ageing", rather than a sickness that might be treated:

> *"The doctor asked Maame what was wrong with her and she said her knee and her waist were paining her and the doctor gave her medication for those pains … she is still complaining, so me, I have concluded that it is because she is very old." [HH BB 0731; Daughter of IOP]*

6.5.2 Traditional/herbal medicine

Half of the ten households interviewed reported using traditional medicine, specifically herbal medicine, to treat ***'Nkokora' / 'Mmrewa' yarie*"** (Twi version of old men/ old women disease). However, in some cases, they reported using a combination of TM and WSM for the same condition, but for tackling different aspects of it:

"When it happened, we were told that we can only use traditional medicine because of the nature of the fracture…and that is what we did…we were told to put some herbs on the affected area after we had massaged the area with a hot stone…other times to I buy some drugs that works on the bones for her to swallow" [HH BB 0731; Daughter of IOP]

They also reported switching from the TM to WSM, or the other way around, if their assessment of either treatment models were found to be ineffective. A caregiver said:

"M: Great…very interesting…shall we continue? This sounds like you have tried the traditional treatment before…tell us".
"R: Yes…at the beginning we used it but when we realized that she was not getting well we sent her to the hospital". [HH AB 0075: Grandson of IOP]

A caregiver from one family and an index older person from another family who believed that supernatural forces were the primary cause of the cognitive symptoms specifically sought traditional TM or faith-based healing and not WSM. This was in line with their beliefs; that the only appropriate treatment for their older relatives' problem was TM and not WSM. They remarked:

"…when I realized that something was wrong with him…I contacted my uncle at Baniantwe and he informed me dwarfs wanted to possess him and he rejected it that is why he sometimes behaves like that." …he gave some medicine to me…they were herbs…he prepared some for him to bath with…and immediately after bathing with the herbs those things he does as if dwarfs have possessed him stopped. [HH AS 0533; Son of IOP]

"When it started he could not talk or walk…we did not send him to hospital to treat this kind of illness…we only used the traditional medicine and we saw that there was an improvement because he could walk..." [HH NN 0133; Son of IOP]

6.6 Care arrangements

The arrangements made for the care of older persons in Kintampo reflected on gender basis in terms of who made decisions and what roles and aspect of the care families were involved in, as well as in what capacity.

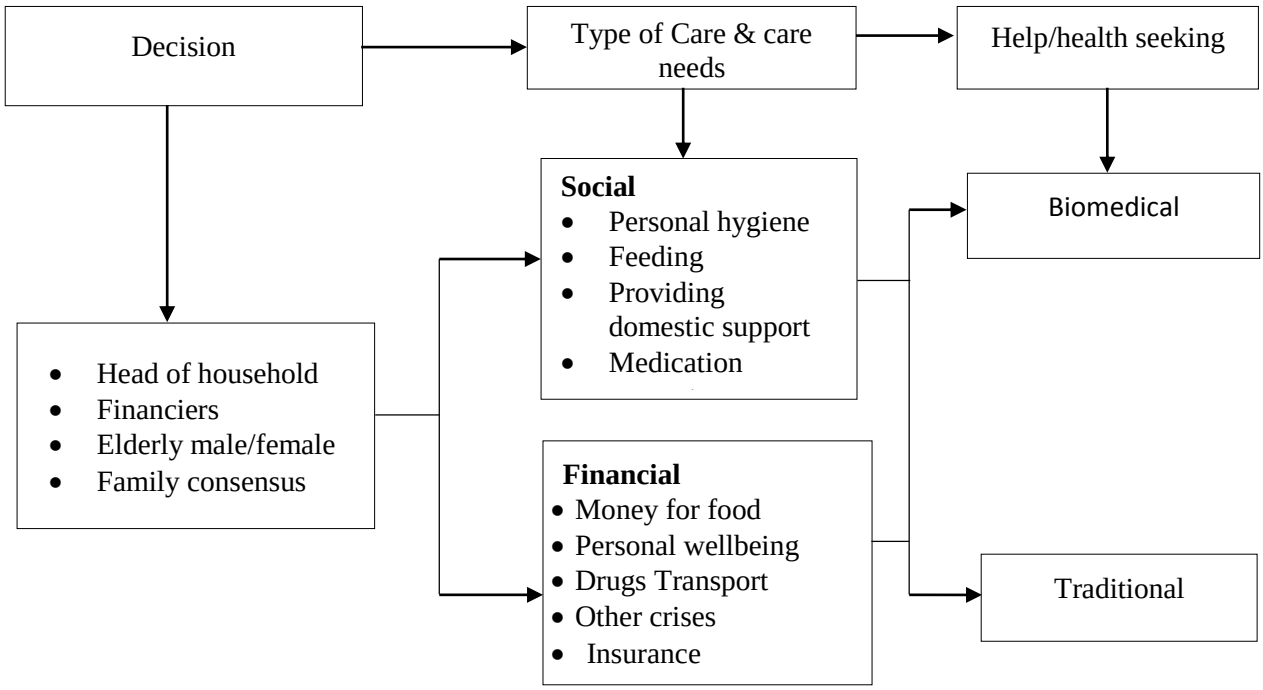

Figure 10: Framework on decision making process, care arrangements, and help/health seeking

6.6.1 Women as de facto carers

All the four male index older persons had wives, but the six female index older persons did not have husbands; they were widows. Female relatives, or wives, were the hands-on caregivers. Female relatives became hands on caregivers or assisted in the daily care if they were the oldest sibling, had returned to live with an older parent because of divorce, or to help recuperate from an illness. The wife of the older person, as well as other women in the household, assisted the older person with other activities of daily life: bathing, preparing food, dressing, toileting, and ensuring they were not left alone (for fear of getting lost). Being a caregiver for a husband was an integral part of being a wife, and providing care for the older members of a husband's family was a natural extension of this role.

> *"I make sure she gets food to eat every morning. If I do not cook in the morning, I go out and buy food for her, then in the afternoon I will buy porridge [she likes that very much] for her. In the evening I will cook supper for her. When she complains of any form of aches then I will go buy medicine for her to take for her pains…that is why I stopped Hasia from selling yam so that she will come*

and support take care of Maame…so in the morning she sweeps and give her water to bath and also make sure there is food for her to eat…" [HH BB 0731; Daughter of IOP]

"My mother is responsible for fetching water for his bath and when my mum is not there, my sister will assist with that. If both of them are not there my wife or I will take up such task…but I am the one who takes him to the hospital…" [HH AS 0552; Son of IOP]

"My grandmother is not doing anything, so she has been taking care of him…when my grandmother travels one of my "mothers", who lives with them at Asantekwa takes charge and even some of the grandchildren after they have returned from school do some of these activities." [HH AS 0552; Grandson of IOP]

"For the old lady…prepares his meals…she boils water for him to bath with and helps in washing his clothing and of course she stays here at night with him and watches him." [HH AS 0533, Son of IOP]

One of the daughters of an older lady stated that she was the main caregiver as she was the eldest sibling and divorced from her husband:

"…so I am the person here always so I am the one who provides care" [HH OP 0088; Daughter of IOP]

However, in one case a male was the hands-on caregiver. Where there was a man involved in day-to-day activities with the older person, they identified themselves as the primary caregiver and involved themselves with such tasks as: fetching water for their bath, ensuring they have their meals, assuming the role of decision-maker about other care and treatments; arranging transport to healthcare appointments, and supervising medication, as well as assuming the role of financial responsibilities.

"In terms of going to the hospital, I usually accompany him and sometimes I call my nephew in Kintampo then he will come and meet us at the hospital…my nephew has a motorbike so sometimes he comes to pick him to go to the hospital. At times too Papa and I will pick a vehicle from here and my nephew will meet us at the hospital and will pay for everything including hospital bills…he takes care of that…he has the money and takes care of that…he is the one who goes to the hospital every month for his medications and sends them to us here at Asantekwa." [HH AS 0552: Son of IOP]

"I make sure he has something to eat and if he has drugs to take, I supervise him to take his drugs…the old lady she only prepares his meals and not

supervising him to take his medicine…I do that…we follow the doctor's advice." [HH AS 0533; Son of IOP]

"All of us take care of Papa…the ladies who are married live with their husbands and offer support when they pay Papa a visit…but when they go, everything rests on the shoulders of the sons to care for him." [HH NN 0133; Son of IOP]

Others became de facto caregivers because of their geographical proximity to the older person and the absence of possible candidates for the role. For example, a son who was a caregiver described how all his siblings had migrated from the village to look for greener pastures, leaving him and his wife as the only suitable caregivers for his mother. For the only male hands on caregiver (grandson of IOP), the polygamous marriage of his father meant that he spent several months of the year in the North of the country leaving him to care. He said:

"…sends her to the hospital and then I call and tell him [his father] about it later…then he will tell me what I should do or he will come if he has to be here" [HH AB 0075; Grandson of IOP]

6.6.2 Decision-making

Whilst decision-making was a primary component of the role of male caregivers, some female caregivers were decision-makers in addition to being hands-on carers (usually daughters of the older person). More commonly though, women who were not the daughters of the older person played no substantial role in decisions about treatment. Some primary caregivers made unilateral decisions about treatment. They informed those family members not resident in the compound, and who might be expected to contribute financially to the care of the older person, after the decision had been made and treatment accessed:

"I will usually send him to the hospital first and then inform my other siblings later on… I will have to look for money and send him…at times too my other siblings can bring a car from Kintampo to send him to the hospital…we also have other relatives who help when papa is unwell. However, here in this village I take care of everything and even his insurance." [HH AS 0533; Son of IOP]

In other cases, the families came together to discuss decisions. They agreed on the specific roles and responsibilities for family members on the financial and physical care of their index older persons. There were also others who made unilateral decisions or were limited in their role to make any meaningful decisions unless they waited for the head of household, often a male. One participant responded:

> *"One person cannot decide on this issue. It was the decision of the family members that, where Grandpa's age has gotten to it is important we take good care of him. I mentioned this earlier on that those who have travelled contribute their monies and send the foodstuffs we buy to them. My grandmother is there with other family members so those living with him help him with his daily activities…when it comes to bathing, my grandmother is responsible; for his meals, it is my grandmother. My uncle and my aunties…they share those responsibilities and make sure that it's been taken care of…" [HH AS 0052; Grandson of IOP]*
>
> *"I have done nothing…we are just there…if something happens for instance to Ima I can send her to the hospital and then call and tell him about it later…then he will tell me what I should do or he will come if he has to be here [HH AB 0075; Grandson of IOP]*
>
> *"I have other brothers in Kumasi who also sends money to support us … there are three brothers who live in Kumasi now and they all contribute financially to support with Maame's care … if one doesn't have money the others will take it from there." [HH OP 0088; Daughter of IOP]*

6.6.3 Division of labour

In general, caregiving was a collective activity; with hands on care duties mostly shared among the female members of the large compound households in which the older people co shared with children, grandchildren and, sometimes, great grandchildren. Sometimes these arrangements were co-ordinated by a primary caregiver, but more commonly amongst siblings and their children within two or three generations. The arrangements that those involved in care were most able to rely on was supplementary support, as and when it was necessary:

> *"Yes…since there are many of her grandchildren around the duties have been shared amongst them. Initially when you tell them to prepare food they will be looking at each other not knowing who to do what…when you do not mention someone's name then they will be sitting down…so I met with them and*

apportioned duties for each of them. The schedule is changed every three days to ensure that each and every one is doing something" [HH BN 0089; Daughter of IOP]

"If I need to go out anyone in the house will have to take care of her until I return to take over. We are many in this household…each one of us helps. If I am not there any one of them in the house will take care of her. We all cannot leave her alone in the house…always we have to make sure someone is at home with her…when she is sitting alone, she thinks a lot so we make sure there is someone with her every time to chat with her..." [HH OP 0088; Daughter of IOP]

6.7 Economic impact

The financial bearing on a family when caring for an elderly person, especially one who is affected by dementia, can be seen as four pronged in this setting; income generation, multiple demands, indirect costs and uncertain trajectories.

6.7.1 Income generation

The families involved were mainly engaged in subsistent farming. Hence, work schedules were flexible enough to engage in other activities when the need arose without hindrance. This was especially so when care needs were minimal, and in the day-to-day care of older persons shared among many. As a result, generating an income, or subsistence activities, were not affected: One stated:

"Maame's condition has not reduced the work I do in any way…even if I go to farm there is someone who helps to care for her…we are many here so every time, there is someone at home so if you are not at home you are not worried. Maame also has many grandchildren it is not a problem to leave her for a while and go to the farm to work…they take care of her needs…she can also do some things for herself" [HH OP 0088; Daughter of IOP]

However, when looking within the context of minimal care needs, if the concentration of care responsibility is on one individual, resulting in limitations to the amount of time that could be spent away home, caregivers' potential to earn an income is restricted. One caregiver said:

"At first I could go far away from here and work on other individuals' farm for money…but now I cannot leave and go and work on these farms again…I have

to work close to the house so that if she needs something I can do it for her" [HH AB 0075; Grandson of IOP]

6.7.2 Multiple demands on family resources

Dementia is cared for in the context of a multitude of pressing demands on family's psychological and financial resources. In relation to the material resources involved, the family's finances, childcare and schooling, a poor harvest, sickness of a family member, and essential building works all compete with the need to care for the older person:

> *"As you can see these days money is difficult to get…all of my other siblings are married and have children to take cater for…they pay school fees and other things so in terms of money it is very difficult to come by…but when this building almost collapsed it was my sister who gave us money to rebuild and maintain it. When I also fell sick my sister gave me money to go to the hospital and they told me it was high fever…you see when we were rebuilding the house I roofed the house and a nail pricked me the time I was doing it but I did not tell anyone…my foot swelled and I could not wear a shoe…" [HH AS 0533; Son of IOP]*

6.7.3 Indirect costs

Apart from one, all interviewed index older persons had public health insurance. Having health insurance meant that there was no immediate cost to physical access to diagnosing a physical health condition. But other indirect costs; transportation to and from the health facilities, prescriptions for medications that were not available in the health facilities and herbal medicine remained. The one who did not have public health insurance reported that financial constraints limited access to treatment.

> *"I am talking of the means…that is money to send her somewhere for her condition to be treated…we don't have it…I am even talking about her eye problem, if I send her to the hospital they can treat her at the hospital…but I don't have the means…if I had I will look for treatment for her eye problem to go away so that she can see well" [HH AS 0815; Son of IOP]*

> *"My son and his wife help me care for him and they contribute financially also when was not well and we sent him to the hospital…but there were times we had to wait because there was no money and take him when we have money…pause…it was mostly to pay for the transport…there were times we needed money to buy drugs if they don't have some in the hospital." [HH NN 0081; Wife of IOP]*

However, one family mentioned that they received some support from government. The Government of Ghana rolled out a programme called the Livelihood Empowerment against Poverty (LEAP) to support the aged and started with those in the rural areas. The aged are given GHC 48.00, approximately £10 or £5 per month (per the Exchange rate at the time of the interview). The index older person in this family was a beneficiary. The caregiver said:

> *"…then the other support we receive is the money the government give to the aged in the community…they are given some money every two months That is the only other source of support I can say we receive." [HH BN 0089; Daughter of IOP]*

6.7.4 Uncertain trajectories

To most of the families, the course of the health of their older relatives was unclear and therefore the management of future costs associated with illness was a source of concern:

> *"We know that she will not live forever and die one day…she can live very long or even die tomorrow but when she grows very old and has all kinds of small, small illnesses that is where the problem can be…we don't know when she will tell us this part is paining her and we two we don't have the means …" [HH AS 0815; Daughter-in-law of IOP]*

Whilst this may be the case for most of the families in this rural community, two families mentioned they did not have such economic challenges:

> *"…In terms of money, it has been the responsibility of my three "mothers" and myself. Wednesdays being market days, we will buy foodstuffs and meat from the market and send these items to the family in Asantekwa to prepare food for Papa. Sometimes, this can last for week or depending on the quantity and kind of things, we buy...at the end of the week or month, we contribute and buy new stock of foodstuffs for them. I also visit them regularly…it has not affected my finances and it will not affect anyone" [HH AS 0552; Grandson of IOP]*

6.8 Community perceptions of older people living with problems of the mind

Older people were perceived to lack understanding. Caregivers reported older persons threw tantrums when least expected, which they described as being 'childlike'. For example:

"I think that some of them are due to old age…now she is old and her mind has turned to be like the one of a child." [HH BN 0089; Daughter of IOP]

"Because of her age she now behaves like a child…" [HH OP 0088; Daughter of IOP]

"I told him that my father talks and behaves like a child...he did not tell us anything…" [HH AS 0533, Son of IOP]

Most caregivers reported that their older relatives had not experienced any situation perceived to be stigmatising. They rather made positive remarks about most members of the community and how they related to their relatives living with dementia. They described how friends and neighbours came over to visit, asked how they were doing, chatted with them and generally extended support and love to the older person.

…" they say he is very quiet […] he does not like talking, he does not bother anyone … whatever you do he will accept, and he has been like this for a long time …because of that no one says anything bad against him". "There has not been an incident like that. Sometimes when he goes out and we complain some of them will even tell us to exercise patience with him. They will explain to us that he is doing these things because of his age … they always advise us to take him like that." [HH NN 0081; Wife and daughter-in-law of IOP]

The extended support manifested in community members who came by to spend a few minutes with an affected person or escorted a lost affected person back home.

Getting lost, difficulties in having conversations, and forgetfulness were accepted as symptomatic of ageing when exhibited among older people, rather than "madness". As such, older people who displayed these behaviours might experience some "teasing" from small children, but this was not felt to violate the respect accorded to older people:

"R1: Sometimes some of the young people pass by to spend time and try to share jokes with him but they are not disrespectful…" "The way he speaks…he will say "give me Simpoa" (a smaller denomination of currency that was previously used and mainly given to children) …so they share such jokes with him." [HH AS 0533; Son of IOP]

6.8.1 Changing role of the older person

Most participants reported a role reversal for the index older persons. They saw their loved and supportive adult regress from an able, vibrant person to a perceived dependent toddler:

> "*It is because of the fact that when they are ageing then they start behaving like children who are about to start walking" [HH AS 0552; Son of IOP]*
>
> *"…now she is old and her mind has turned to be like the one of a child." [HH BH 0089; Daughter of IOP]*
>
> *"Oh…we are not bothered at all…we take things like that…she is our mother so if we don't tolerate her then…and if she even sees that you are annoyed by her behaviour she cries and thinks so we just can't tolerate her." "...we play with her…we sit with her and she sometimes tells us stories and things that happened long ago…like what happened when she was very young…happy times…" [HH OP 0088; Daughter of IOP]*

Others reported they had experienced "loss", linking it to a transition in role of the older person, as being someone who was valued as a confidante and an advisor to someone who needed to be advised and whose opinion was, regretfully, no longer trusted or valued:

> *"When she was a bit younger, I used to come to her for advice which were very useful when I follow them…but now if I come and ask her for advice…what she will say does not bring anything good in my life. I have realized I do not have anyone who will advise me again…when I think about these things then I begin to cry…that is why I say I am worried about her" [HH AS 0815; Son of IOP]*

6.8.2 Other - autonomy

Other aspects of the transition in the role of the older person, due to the signs and symptoms of ageing, appeared easier for families to manage. For example, three of the caregivers mentioned that, although they recognised that it was no longer possible for the older person to carry out farming; go to the market; and/or prepare meals as they once did; the value of occupation was still acknowledged by families and older people were encouraged, and supported, to carry out alternative meaningful daily activities:

"…She can do a lot of things on her own with her hands and when she is sitting down…you can see her dehusking the maize for the poultry…" [HH AB 0075; Grandson of IOP]

"She will fetch water and wash them herself. Instead of her sending the kids to fetch the water for her, she doesn't but rather she will drag her feet on the ground to go and fetch the water for washing all because she wants to stay active" [HH OP 0088; Daughter of IOP]

CHAPTER 7

7.0 Discussion

My approach: a cross-sectional survey with embedded qualitative study, is novel. Although there is an emerging bdy of evidence relating to the prevalence of dementia in this region, there is relatively little qualitative evidence relating to beliefs, ideas, experoences and behaviours associated with living with dementia (Guerchet et al., 2017). No studies which used a combination of quantitative and qualitative methodologies to explore this topic were identified. This approach enabled me to obtain a more comprehensive picture of caregiving and its impact, providing evidence to support possible mechanisms for quantitative findings.

7.1 Methods

Sampling

A key strength of this study was that it was carried out in a DSS. I was able to sample within a population which was accustomed to research. This helped us to devise a plan that was feasible within our timelines for the field work. It also reduced potential challenges I might have encountered had I attempted to carry out a standalone study. Despite the support of the research infrastructure in Kintampo, I encountered several challenges which may have affected the representativeness of our sample. A higher refusal rate was observed for older people from the Muslim community (57.7% of the non-respondents). The higher refusal rate may be explained as due to concerns from Muslims families regarding my study, the detailed assessments and the interview of key informants. Strategies to address and overcome these issues should be discussed with the KHRC, local chiefs and religious leaders in order to increase the acceptability of such interviews before implementing further studies among older people in Kintampo. The potential lack of representation of dementia among Muslim populations must be considered when generalising prevalence estimates from a catchment geographic area to similar communities; neither may national representativeness be assumed.

Dementia diagnosis

This study was the first to use the short 10/66 diagnostic schedule and algorithm in a survey of dementia prevalence in a Western SSA country. We had a relatively high response rate of 84.5%. As we used the short 10/66 short diagnostic schedule in the place of the much longer standard 10/66 schedule, it prevented the undue, prolonged questioning of index older persons. It also helped the team to conduct the study within our timelines. The primary purpose of the 10/66 programme has been, and continues to, generate epidemiological research evidence on dementia prevalence, incidence, and impact in low and middle income countries to correct evidence gap. We used a one-phase design and were therefore able to avoid the loss to follow-up, which frequently occurs during multi-phase study designs. A key limitation of this study was our reliance upon a probabilistic algorithm as the measure of dementia status; in the absence of a clinical diagnosis, we can only describe our outcome measure as "probable dementia."

The short 10/66 diagnostic schedule includes a depression scale (Euro-D) rather than a complete mental health assessment (GMS), and can potentially result in some incorrect classification of dementia in people with depressive disorders or other mental health comorbidities (Stewart et al., 2016). Although the Euro_D scale had been previously used in this setting, and careful translation processes were conducted, no formal validation study had been conducted prior to our use of this tool in our study. The objective of the standard and short 10/66 schedules and algorithms is to provide a probabilistic estimation of dementia rather than apply a diagnostic criterion, and no grading of dementia severity is generated.

While the short 10/66 dementia diagnostic schedule and algorithm showed acceptable levels of performance, and coincided with the standard algorithm classifications in survey samples

during its development and pilot testing phases, it must be acknowledged that the data available from the 10/66 pilot samples (n=2885) have mostly come from LMICs in Latin America (n=1682) and in Asia (n=1127), rather than SSA (ie. Nigeria, n=76). Levels of education, literacy, and numeracy could be very different in Ghana, and many other sub-Saharan countries, compared to the other geographic regions where the 10/66 dementia studies have been conducted; this may potentially impact the robustness of the diagnosis of dementia in such a context. Education was previously reported to be a significant predictor of dementia in Tanzania using 10/66 criteria (Paddick et al., 2013), where people with no formal education were significantly more likely to be diagnosed with dementia according to the 10/66 criteria. Although it was not explicit whether this association between education and 10/66 dementia was genuie or the result of an educational bias within the diagnostic instrument. More recently, data from all of the study countries using the 10/66 dementia diagnostic assessment and algorithm in SSA (Nigeria, South Africa, Central African Republic, Congo and Tanzania) were used to assess the validity of its core measures (Guerchet et al., 2017a). Variations in score distributions, both among and within centres, were much greater in SSA than were observed in other 10/66 regions. Informant reports of cognitive and functional decline (CSI-D RELSCORE) or depression symptoms (EuroD) were mainly affected, rather than the assessment of cognition (CSI-D COGSCORE), leading the authors to think that measurement bias might have occurred due to greater challenges in the cross-cultural adaptations of the tools between SSA countries and other regions.

When examining the performances of the participants on the different components of the 10/66 dementia algorithm (COGSCORE, RELSCORE and Euro_D), participants not identified with probable dementia still obtained low scores on cognitive testing (COGSCORE). Several explanations can be drawn from this: they may have had mild cognitive impairment without

any impact on their daily life, they may have been exhibiting symptoms of depression, or they may have had an alternative diagnosis (delirium, HIV-cognitive impairment, etc). When comparing with the probability of dementia provided by the combined score of both components of the CSI-D (ie. DFSCORE), I found that 0.64% of the 'non-cases', 9.37% of 'possible cases' and 65.79% of the 'probable dementia' cases were found to be cases of probable dementia according to the brief 10/66 algorithm. The agreement on the diagnosis of 'probable dementia' was better in our study than in the 10/66 prevalence survey across LMICs, where 0.2% of the 'no dementia', 2.1% of the 'possible dementia' and only 36.5% of the 'probable dementia' were assigned a 10/66 dementia diagnosis. However, we cannot exclude the possibility that some dementia cases might have been missed, leading to an underestimation of the prevalence of dementia in this study. Only clinical assessment would have allowed me to investigate this and would have supported the generation of further evidence regarding the validity of the dementia diagnosis made using the 10/66 short assessment. Clinical assessment was not possible given the duration of time allocated for my study, the funding restrictions and the lack of local specialist resources. No definite conclusion regarding the validity of the 10/66 short dementia schedule and algorithm can be drawn from my study. Given that the sub-sample who screened positive for dementia were used as the sampling frame for the qualitative study, this limitation extends to this aspect of the project.

Due to the lack of clinical assessment, the ascertainment of the different sub-types of dementia was also unavailable in our study. The diagonsis of subtypes of dementia in SSA, as in other LMICs, can often be challenging. The lack of both neuroimaging and dementia specialists often limits the possibility of subtype diagnosis; most diagnoses are reliant upon clinical judgement and the presence of vascular risk factors alone (Guerchet et al., 2009; Guerchet et al., 2010; Guerchet et al., 2013a).

7.2. Prevalence of dementia in rural Ghana, Kintampo

This study supports the assertion that dementia is a growing public health challenge. The crude prevalence of dementia in Kintampo using the 10/66 short algorithm was 4.9% and the standardised prevalence was 6.6%. The prevalence in Kintampo is therefore within the range of regional estimates reported: 5.5% to 7.2% (Prince et al., 2015a). The crude prevalence (4.9 %) in Kintampo is similar to the prevalence estimates presented in the meta-analysis of GBD Africa, as published in the 2015 World Alzheimer's Report, and is slightly higher than that reported for three of the SSA Regions: Central - 4.4%; East - 4.5% and West - 3.9%.

This is the first population-based study on dementia conducted in rural Ghana. It is also the first in the West African Region to study those aged 70 and above using the short 10/66 diagnostic schedule and algorithm. Comparisons of prevalence should be made with caution due to the differing age cohorts found in the studies conducted in sister SSA countries, as well as the different diagnostic criteria used (DSM vs. 10/66). Most studies carried out in SSA to date included older people aged 65 years and above, while our study included individuals aged 70 years and above. The only study from SSA using a similar age cohort was conducted in East Africa (Tanzania) by Longdon et al., (2013). However, dementia was diagnosed in this study using the DSM-IV criterion, not the 10/66 criterion. Study design (one-stage vs. two-stage) and sampling strategies also differ from one study to another (Table 25). Therefore, any comparisons on prevalence must be seen in this light.

The crude dementia prevalence estimated in this study is slightly lower than those previously reported in Central Africa in the 'Epidémiologie des Démences en Afrique Centrale' (EDAC) study and, more recently, in the 'Epidemiology of Dementia in Central Africa' (EPIDEMCA) study, ranging between 5.7% and 8.1% (Guerchet et al., 2010; Guerchet et al., 2013a). In contrast, a lower prevalence of dementia has been consistently reported in studies from West Africa: 2.3% (urban Nigeria) (Hendrie et al., 1995) to 3.7% (urban Benin) (Paraiso et al.,

2011).The prevalence estimated in this study falls within the same range as the limited evidence from East and South Africa (see Table 25). In addition to the higher threshold for age in our study, another possible explanation for the higher prevalence in Kintampo compared with the other West African studies might be due to Ghana having one of the most rapidly ageing populations in the Region (Mba, 2010), as well as people living longer lives.

Table 25 Studies on dementia in sub-Saharan Africa: characteristics and prevalence.

Reference	Country, region/city	Rural / urban area	Design	Sampling	Lower & upper age limits	Sample size	Numbers interviewed (proportion responding)	Diagnostic criteria	Prevalence (CI95%)
Hendrie et al., 1995(Hendrie et al., 1995)	Nigeria, Ibadan	urban	2-stage	Door-to-door	≥ 65	2535	2494 (98.4%)	DSM III-R/ICD10	2.3 (1.2-3.4)
Guerchet et al., 2009(Maelenn Guerchet et al., 2009)	Benin, Djidja	rural	2-stage	Catchment area*	≥ 65	514	502 (97.6%)	DSM-IV	2.5 (1.1-3.8)
Yusuf et al., 2011(A. J. Yusuf et al., 2011)	Nigeria, Zaria	urban	1-stage	Systematic random sampling	≥ 65	322	322 (100%)	DSM-IV / ICD10	2.8 (1.0-4.6)
Paraiso et al., 2011(Paraiso et al., 2011)	Benin, Cotonou	urban	2-stage	Random sampling (Proportional)	≥ 65	1162	1139 (98.0%)	DSM-IV	3.7 (2.6-4.8)
Ogunniyi et al., 2016(Ogunniyi et al., 2016b)	Nigeria, Lalupon	rural	2-stage	Catchment area*	≥ 65	642	642 (100%)	DSM-IV	2.9 (1.6-4.4)
Guerchet et al., 2010(Maelenn Guerchet et al., 2010)	CAR, Bangui	urban	2-stage	Catchment area*	≥ 65	509	496 (97.4%)	DSM-IV	8.1 (5.8-10.8)
	Congo, Brazzaville	urban	2-stage	Catchment area*	≥ 65	546	520 (95.2%)	DSM-IV	6.7 (4.7-9.2)
Guerchet et al., 2013(Guerchet et al., 2013c)	CAR, Nola	rural	2-stage	Catchment area*	≥ 65	501	473 (94.4%)	DSM-IV	8.5 (6.1-11.3)
	CAR, Bangui	urban	2-stage	Random sampling (Proportional)	≥ 65	514	500 (97.3%)	DSM-IV	6.4 (4.4-8.9)
Guerchet et al., 2013(Guerchet et al., 2013c)	Congo, Gamboma	rural	2-stage	Catchment area*	≥ 65	529	520 (94.3%)	DSM-IV	5.7 (3.8-7.9)
	Congo, Brazzaville	urban	2-stage	Random sampling (Proportional)	≥ 65	537	500 (93.1%)	DSM-IV	6.6 (4.6-9.1)
Longdon et al., 2013(A. R. Longdon et al., 2013)	Tanzania, Hai	rural	2-stage	Catchment area*	≥ 70	1260	1198 (95.1%)	DSM-IV	6.4 (4.9-7.9)
Vanderpoel et al., 2013(Vanderpoel R. et al., 2012)	South Africa, Muangang	urban	1-stage	Catchment area*	≥ 65	230	206 (89.6%)	10/66	6.0 (-)

* Door-to-door

In comparison with the evidence generated by the 10/66 DRG in other countries, using similar methods and a similar diagnostic criteria, the prevalence in Kintampo approaches those estimated in rural Peru (6.5% (95% CI: 4.4-8.6)), Venezuela (5.7% (95% CI: 4.7-6.8)) and rural China (5.6% (95% CI: 4.2-7.0), whilst other settings in Latin America, India and China had a higher prevalence of dementia (up to 11.7 % (CI: 95 % 10.3-13.1) in Dominican Republic) (Rodriguez et al., 2008).

A few considerations must be acknowledged whilst interpreting our main result on the estimation of the prevalence of dementia in Kintampo:

1. Prevalence estimates might have been affected by our sampling technique and their generalisability to the entire Kintampo Municipality cannot be assumed. Indeed, the sampling conducted in the KHDSS originated from the KHRC which is located in a densely populated area of the Kintampo North Municipality, and next to one of the two main district hospitals. The population included in our sample might therefore be more likely to have better access to care, as well as be more likely to have a better socio-economic status than people living in villages further from KHRC which would be likely to impact on their likelihood to develop dementia in old age. Although our sample includes participants from both Kintampo North and South districts and demographic characteristics are consistent with ethnic and religious diversity found in the region, I cannot exclude other differences between those inclused in the sample and those not included that may have had an influence on participants' risk of developing dementia. Therefore, the prevalence estimates presented here can only be safely applied to the districts included in the study, rather than being generalisable to the region as a whole.
2. I cannot completely rule out the possibility that people with dementia may have been missed at the time we carried out the study. Indeed, a low number of participants reported having a disability. Disabled people, and people with more severe dementia, might have

moved out of the DSS and/or our study area to live with different relatives where more support was available, or in areas with better access to care. We excluded three potential participants (0.3%) from our sample because they were severely ill. Although we referred these individuals to appropriate health services, their short-term prognosis and conditions were not good enough to consider interviewing them. Unfortunately, the reasons for their poor health were not known to the team of interviewers, and so we cannot exclude the possibility that these individuals had dementia. If this is the case, it might have led to an underestimation of the prevalence of dementia in this study. Lastly, the relatively low prevalence estimated in this area could be due to the shorter survival of older people living with dementia, which has been previously reported in other low-resource settings (Prince et al., 2012).

3. Given that the prevalence of dementia doubles with every five-year increment of age, accurate ascertainment of is of vital importance. We therefore place special emphasis on this factor during the training. Although our study was conducted in a DSS where birth certificates are issued for the population, older people are more likely to lack reliable documentation of their age. According to the methods used by the 10/66 DRG in several LMICs, including Nigeria, multiple sources of information were used to determine the age of the participants. However, in our study, 97.8% of the participants could provide an official document stating their age. Greater discrepancies (> 2 years) between this one and the age reported by the participants themselves or the informant was observed for 30% of participants because they were unable to provide their age when asked. While these discrepancies were eventually adequately explained, the age considered accurate was often one estimated through life events (using the events calendar) relevant to the population. Local events or historical calendars are compiled of significant local events which people of low or no education should be aware of. They are also an additional certified source in Ghana used for population censuses (Ghana Statistical Service, 2014), and by the three

DSS sites mentioned earlier. In the case of this study, the KHDSS made their official local/historical calendar available for our use during the interviews. This method has been validated in two other countries of West Africa (Nigeria (Ogunniyi & Osuntokun, 1993) and Benin (Paraiso et al., 2010)) and successfully used in several dementia studies conducted across SSA (Paraiso et al., 2011; Guerchet et al., 2009; Guerchet et al., 2014; Guerchet et al., 2010). Although the events used in our population to estimate participants' ages were not formally validated, the relevant events chosen for our population were of approximately the same time frame as the ones validated in Nigeria and Benin, which respectively showed a Spearman correlation coefficient of 0.989 (Ogunniyi & Osuntokun, 1993) and an Intraclass Correlation Coefficients of 0.87 (Paraiso et al., 2010). Moreover, the difference between the actual age and the estimated age in those studies was rarely greater than 5 years. In this study, a few participants (n=13) were attributed ages equal to or greater than 100 years old. It must be acknowledged that such outliers, despite the use of several sources of information, might reflect a lower accuracy of the estimation of age amongst the oldest old.

Overall, the dementia prevalence estimated in this study could have been impacted in two different ways: - by overestimating dementia prevalence amongst the oldest groups if the age of participants was also overestimated, and - by underestimating dementia prevalence in the overall sample if the age available in the DSS records (on which our sampling relied) was overestimated and led to the inclusion of participants younger than 70 years old.

7.2 Associations with dementia

In my study, increasing age was associated with probable dementia. Indeed, crude prevalence increased with age, with a 5.36 times higher prevalence of dementia for those aged 90 years and older. The prevalence of dementia increased exponentially with age; while this association was found in both male and females, the association was higher among women than men. This

is similar to what has previously been reported: age is the strongest determinant of dementia in SSA, LMICs and HICs alike (Ferri et al., 2005; Llibre Rodriguez et al., 2008; Guerchet et al., 2009; Paraiso et al., 2011; Hendrie et al., 1995). However, female sex was not associated with probable dementia in our study. The evidence from other sub-Saharan studies shows a 2 to 8-fold increased risk of dementia among females (Paraiso et al., 2011; Gureje et al., 2011; Guerchet et al., 2012; Ogunniyi et al., 2006). This may be in part due to their longer lifespan. However, the proportion of men and women included in our study was almost equal and their mean age was very similar, which might have led to a lack of power to detect this association. Low education or illiteracy has been reported to be a robust risk factor for dementia. In my study, a trend towards education as a protective factor for probable dementia was found, even after adjustment on potential confounders. The risk of probable dementia tended to be lower for the participants who had had some level of formal education. Most of the older people in the KHDSS had not received formal, Western-style education. This is a common phenomenon for SSA countries in the age group studied. Literacy was very low in this group. Findings from other studies in SSA on the association between dementia and education are mixed (Guerchet et al., 2017b). Other studies that reported a low prevalence of dementia in Nigeria and Benin (neighbouring countries with Ghana) did not find an association between dementia and education (Guerchet et al., 2009; Hall et al., 1998). Although education does not protect individuals from developing dementia, it mitigates the impact of pathology on the clinical expression of cognitive impairment, which is why education is often used as a marker of 'cognitive reserve'. However, level of education might not be a good marker for cognitive reserve for the elderly in this study, where informal and traditional systems of instruction ensure that people are well trained to be able to face the environmental and sociocultural demands brought to them over the lifespan. This may be true in other SSA countries as well.

Lifestyle factors, including diet, smoking, and physical activity, are often identified as determinants of dementia; they can be targeted by brain health and dementia prevention and interventions strategies (Guerchet et al., 2017b). In our study, neither diet nor smoking were associated with probable dementia. In our sample, we found that lifestyle characteristics like smoking and alcohol were associated with sex, with men being more likely to be smokers and drink alcohol. As most of the participants identified with probable dementia were females (25 out of 38), this might have contributed to reduce or conceal any association between smoking and the prevalence of dementia in Kintampo. The respondents in our study reported they were still engaged in physical activities (for example, walking at least 0.5 kilometres daily), which is one of the activities believed to lower risk of dementia (Kalaria et al., 2008). Our findings offer evidence confirming this association: we found that people who were not exercising (walking at least 0.5 kilometres daily) had a 2.5 higher prevalence of probable dementia than the ones who were walking daily. Evidence on physical activity is very limited in SSA. Nevertheless, global evidence from observational studies suggest that physical activity may be associated with up to a 40% reduction in dementia risk; however, results from follow-up studies show inconsistent results (Prince et al., 2014). Although physical activity is often conceived as a leisure activity, physical activity in Kintampo may reflect occupational and social activities which entail psychological engagement and interactions, which may in benefit mental health.

Engaging in social and physical activities that stimulate cognition is hypothesised to lower the risk of dementia (Kalaria et al., 2008). Social interactions and engagement were investigated through attendance to religious meetings, clubs and groups, as well as by the presence of friends in the community. In the study population, having friends was very common (57%) and regularly attending religious events was more frequent than attending other social gatherings (45% vs. 34%). In qualitative interviews, participants described supporting older people to maintain some meaningful activities, albeit in a reduced role, with less autonomy and fewer

responsibilities. However, the only significant association we found between prevalence of probable dementia and social activities was a lower prevalence among those who were attending occasional or regular religious meetings. This is in agreement with previous findings from SSA where living with others was found to be protective against dementia in Nigeria (Ogunnyi & Baiyewu, 2000). Narratives from the qualitative study suggest that older people with symptoms of probable dementia were well integrated within the Kintampo community, with participants describing neighbours bringing older people home when they were lost, for example. Social isolation or a poor social network were also reported to be risk factors of prevalent or incident dementia in other studies from SSA (Gureje et al., 2011; Ojagbemi et al., 2016; Touré et al., 2009).

None of the physical and psychological comorbidities we investigated were associated with dementia prevalence in Kintampo. Participants in the qualitative study commonly reported dementia-like symptoms in the context of symptoms of physical health problems. However, given that we only interviewed people with probable symptoms of dementia in the qualitative study, it was not possible to explore any differences in how of illness of the body and illness of the mind were conceptualised among families of older people living with and without dementia. Strong evidence exists on the association between dementia and hypertension in midlife and diabetes across the lifespan (Prince et al., 2014). Those conditions were only assessed through self-report in our study. Due to limitations in the available funding, were unable to conduct brief physical examinations, such as blood pressure and capillary blood sugar measures. This is a limitation considering that there is a lack of diagnosis for such chronic conditions in populations who do not frequently access health services, as was the case in our sample. A strong association between the prevalence of probable dementia and disability was found in Kintampo, even after adjustment for a wide range of impairments. Previous studies

from the 10/66 DRG have shown that dementia makes the largest contribution to disability in LMICs, with a greater impact than depression, stroke and arthritis (Prince et al., 2015a)

7.3 Needs for care, care arrangements and the economic and social impacts of caregiving

Overall, older participants and their informants reported few needs for care. Among the 38 older people living with dementia, only eight (21.0%) needed more care than the rest of older people without probably dementia, whilst 11 needed similar levels of care as their peers without probable dementia. This finding is not without precedent. In previous 10/66 studies, high needs for care were reported in many sites (15.7% in urban China, 11.3% in urban Mexico and 11.8% in Dominican Republic), while few needs for care were reported among older people and their families in rural India (2.9 %) (Prince, 2004). It is possible that this is due to survivor bias: the field notes from qualitative interviews suggest that, although most of the older people interviewed displayed symptoms of cognitive impairment, many of the signs and symptoms associated with the strain of severe dementia (e.g. agitation, aggression, incontinence) elsewhere (Ferri et al., 2005) appeared to be absent in Kintampo (Ferri et al., 2004). It may be the case that older people who are generally healthier have survived to older ages.

Qualitative work from India suggested that the rationale for the low reported needs for care may be due to the cultural norms of support provided to older people, regardless of their needs (Prince, 2004). Findings from the qualitative component of my study are consistent with this approach to the support of older people. Results suggest that household structure may support the care of older family members and that the work of caring appeared to be more seamlessly absorbed into the daily tasks of the women within large family compounds in comparison with women in Latin America, China and Nigeria. It seems possible that traditional gendering of roles, the salience of seniority and filial obligations remain more strongly intact in this setting, and retain their traditional influence in ordering relations and social actions (Udvardy & Cattell,

1992). Certainly, from the Kintampo interviews, it was apparent that compound household structures enabled amicable distribution of care duties among many individuals. This explains why a very low proportion of informants identified having a 'need for care' in the quantitative component of the study, despite being caregivers.

Traditional gender roles related to caregiving (men as decision-makers, women carrying out hands-on care) appeared to be uncontested in our study setting. Unlike participants in 10/66 sites in urban Latin America, where some women were beginning to challenge their de facto role as caregivers to older family members (Mayston et al., 2017), none of the caregivers (nine females and one male) interviewed in Kintampo questioned their status. These attitudes and practices appear to result in a more harmonious experience for caregivers, which is reflected in the low levels of mental health problems and strain identified in quantitative analyses. There was no significant difference in strain reported by the carers of those with dementia and those without; however, this result should be taken with extreme caution considering the low number of people who were assessed for strain. However, a high proportion (88.7%) of caregivers did not have any psychological morbidity. In other settings (India, China and South East Asia, Latin America, the Caribbean, and Nigeria), the anxieties of being a caregiver and attempting to meet the costs of care were strong themes (Prince et al., 2004; Prince et al., 2012), whereas in Kintampo, though respondents expressed concern for the health of their elderly family member, comments about adverse effects upon their own wellbeing were largely absent from our interviews.

In addition to the advantages of the extended family, the compound household model present in rural Ghana potentially provides sufficient flexibility to accommodate the needs of caregivers to balance care activities with income generation. Given that primary activities in our study site are farming and small trade, and that there is low participation in formal labour, particularly among women, the kinds of economic activities that caregivers were carrying out

were more flexible, and likely to be closer to home than the jobs and careers of women living in urban Peru, Mexico and China (Mayston et al., 2014). In some families, health insurance appeared to alleviate some of the costs of physical health conditions affecting older individuals. However, it was clear that not all families were reaping the potential benefits of health insurance. This may be because health insurance excludes chronic conditions and their attendant high costs of treatment. Other contributory factors include: a large non-formal healthcare sector; rural communities made up of small towns with poor roads; and a poor telecommunications network, inhibiting access to health services (Agyepong & Adjei, 2008). Further research is necessary to understand the specific barriers to accessing health insurance among older people. However, a lack of awareness of the fee exemption for those aged 70 years and above, and inequity of enrolment for poorer people have been highlighted as potential concerns (Lagomarsino et al., 2012).

7.4 Experiences, beliefs and ideas about dementia and how these relate to help-seeking behaviours

Participants in this study conceptualised problems associated with ageing as accumulated "wear and tear" over time resulting from life experiences. Within this explanatory model, participants occasionally made a distinction between body and mind (Patel, 1995) (linking symptoms of cognitive impairment with wear and tear of the brain), however, dementia was not always the most significant component of respondents' experiences. They viewed the health of older people holistically, by describing an overall collection of symptoms, and by observing and responding to needs for treatment and care as they arose. This reflects experiences of health and sickness of older people and their families around the world, where multi-morbidity is common and broad outcomes, such as disability and needs for care, are more salient and important to older people and their families than specific diagnoses and the aetiology of disease.

Perceived aetiology did however play a role in shaping the character of help seeking. The choice of biomedicine, traditional African medicine, or a combination of both depended largely on the availability of the various options (Fink, 1989). As has been found in Ghana and elsewhere, families who believed witchcraft to be the primary cause of cognitive symptoms opted for traditional healing as a first-line treatment (Dale & Ben-Tovim, 1984; Bierlich, 2000; Fink, 1989). In this study, families did not regularly seek treatment of any kind for dementia symptoms in their older relatives. However, they did seek treatment for physical health symptoms and used both traditional medicine and Western-style biomedicine. Yet on two occasions, where perceived dementia symptoms believed to be linked to bewitchment, family members sought treatment from traditional medicine. Among those who perceived ageing as the primary cause of symptoms, experimentation with both Western-style biomedicine and traditional treatment was common. Participants would switch treatment modalities when a particular treatment was found to be ineffectual; this was also found in a study conducted by Bierlich in Northern Ghana.

Ultimately, many of the symptoms of old age were understood to be untreatable and characteristic of inevitable degeneration of old age. Participants commonly located cognitive symptoms in this category. However, in a setting where there is low recognition of chronic conditions associated with old age among health professionals (de-Graft Aikins et al., 2012), it is difficult to ascertain what role the lack of services played in determining attitudes to help-seeking for chronic conditions, including cognitive impairment. The absence of appropriate services for chronic conditions in the elderly, and perhaps an associated view wherein cognitive symptoms were believed to be untreatable, may have contributed to a lack of focus upon cognitive deficits in the in-depth interview narratives.

When asked, participants reported that stigma towards older people living with dementia did not exist in this setting: it was reported that community members extended support through

visits, continued respect for the elderly and had general good will towards affected older persons and their families. Changes in behaviour and actions in elderly people were recognised but attributed to "normal ageing"; this may function to support the continued integration of older people with probable dementia within their communities. Nonetheless, it is clear from the qualitative narratives that older persons living with problems associated with the mind were considered to have diminished roles in their families and society at large. Caregiver participants characterised the roles of older persons as being reversed; moving from acting as head of households and caregivers for children, to being seen as dependent and childlike as they aged.

7.5 Conclusions

What is the prevalence of dementia?

Significant challenges remain in the establishment of the validity of a cross-cultural diagnosis of dementia in population from SSA countries, which involves having a clinical diagnosis as a gold standard notwithstanding the lack of health services for dementia and older people. The prevalence of dementia estimated in Kintampo was within the range of the meta-analysed estimates for the SSA region, both in terms of crude and standardised measures. Differences in methodologies (age, sampling and diagnostic criteria) with the other studies carried out in the region are numerous and limit direct comparisons with those estimates. However, as expected, the prevalence of dementia increases with age, with females at risk for higher prevalence.

What socio-demographic and care related factors are associated with dementia among older people in rural Ghana?

Factors associated with dementia in Kintampo were generally consistent with the evidence from other studies in SSA and LMICs. In addition to our study findings, other countries in West Africa found a lack of association between dementia and level of education and a positive effect of attendance to religious meetings; these findings may be linked to the informal systems

of instruction, as well as the greater levels of engagement in social activities and interactions traditionally encountered in this region and in other rural areas. The contribution of dementia to disability, measured in many LMICs, is confirmed in our study population. Finally, the association between dementia and physical exercise is a novel one for this region, where evidence on physical exercise is limited.

What are the experiences and understandings of living with dementia among people living with dementia and their caregivers in rural Ghana?

Our findings demonstrate that families in Ghana have a coherent explanatory model describing the health problems associated with older age, which are characterised as natural decline; beliefs about symptoms related to cognitive impairment are nested within this conceptualisation of natural decline. These beliefs interact with other, related belief systems such as those describing gender roles, beliefs about the importance of seniority and filial duty, beliefs about health, sickness and personhood in old age, and approaches to caregiving, help seeking and the role of older people. Compared to other places, caregiving seemed to be more comfortably integrated into female roles in Ghana, which, in turn, appeared to result in less strain than has been reported elsewhere. The state is largely absent from people's experiences of living with dementia, both in terms of financial support and health services that are designed to meet older people's needs.

My findings should be treated as an exploratory first-look at the topic in question. Study limitations described elsewhere mean that it is difficult to assess to what extent the transferabililty of findings may apply (limitations include: relatively small sample size; enabling examination of major themes only; overall design of the quantitative survey (and the issues around validity of the diagnostic algorithm); as well as the lack of older people's voices

in interviews. Nonetheless, my work points to some interesting areas for future research, as outlined in detail below.

7.6 Implications and recommendations

Our study findings provide several important indications for areas of future research. Knowledge about dementia is an area not commonly researched in SSA and we therefore lack data on the phenomenon. Whilst our findings can be used to add to the existing evidence base on dementia prevalence, further population-based studies are necessary to expand and strengthen the evidence base globally. High quality longitudinal studies should be conducted in SSA; these could allow researchers to better understand the roles played by ethnicity, vascular disease, educational attainment, lifestyle factors and other variables, in influencing the risk for and development of dementia in these populations. The evidence on risk factors for dementia originating in the SSA region is not currently strong: there is tentative evidence from this region in regard to most modifiable risk factors and is mainly reliant upon on cross-sectional rather than longitudinal studies. This is a barrier to the development of effective intervention and prevention strategies which could be adapted to these settings. At the district level, the data from this study can be used to stimulate further aetiological research of dementia. This would provide necessary statistics on profiles of the older persons affected.

More qualitative work will be necessary in order to build upon our findings, which represent an exploratory starting point in understanding the experiences of older persons living with dementia and those of their family members. In the future, it will be important to conduct work with larger sample sizes, and to sample people with a clinical diagnosis of dementia, potentially with a comparison sample of people without dementia, in order to understand the extent to which dementia shapes experiences of caregiving and living with an older family member. Qualitative work is an important component of preparation for intervention and policy development. Qualitative work is essential to understand what kinds of support/interventions

are most valued and which outcomes should be prioritised. Another important field for future examination is an exploration of the perspectives and understandings of dementia among healthcare providers and traditional healers, and the extent of the congruence of these beliefs with those held by older people and family members: these factors are all likely to affect the acceptability and feasibility of interventions.

Situating this study within the KHDSS had some key implications regarding linkage to health care services. Participants identified during our study who had severe health issues (and were therefore not included) were referred (and sometimes accompanied) to health care services. In a later stage, participants identified with probable dementia were informed about and referred to relevant health and social services for support. Our study, like any study carried out in the DSS, ought to contribute to the DSS and provide opportunities to strengthen the linkages to social and health care services.

In addition, results from this study have implications for policymakers and healthcare providers. The prevalence estimates presented in this thesis constitute the only available documentation for policy making, planning and allocation of resources regarding dementia in Ghana, as this is the very first study of its kind. As Ghana's life expectancy continues to increase, there will inevitably be increasing numbers of individuals affected by dementia and other comorbidities. Social policies and the health system are at odds with the experience and needs of older people and their families (World Health Organisation, 2014). It is important that policies acknowledge the continuing social and economic potential of older people, including those living with dementia, for example, by a continued roll-out of social pensions, which have been found to have a positive impact upon the socioeconomic status of the entire household where an older person is resident (Heslop & Gorman, 2002).

Specific challenges in the health system in Ghana include: the lack of guidelines for chronic disease care; erratic supply of essential drugs and equipment at facilities; lack of old age specialists; and poorly trained healthcare workers with insufficient knowledge of common chronic diseases (de-Graft Aikins et al., 2012). There is emerging evidence that effective care for chronic diseases associated with old age, including dementia, can be delivered by non-specialist workers providing outreach to older peoples' homes from primary healthcare centres in LMICs (Guerra et al., 2011; Jotheeswaran et al., 2015). This approach is a potentially cost-effective means to rapidly scale-up the services that will be needed to address the increase in chronic disease that will accompany the rapid ageing of the Ghanian population.

In Ghana, an urgent priority is to speed up the implementation of the Mental Health Act 2012 and facilitate a rapid implementation of the Ageing Policy to scale up the allocation of resources for long term care needs of PWD, including support for family carers. In Ghana, a national policy on Ageing has been completed, in which there are plans to focus and target the prevention and management of chronic NCDs, including hypertension, diabetes, atherosclerosis, stroke and coronary heart diseases (Government, 2010). In the policy document, there are plans to train the health workforce in geriatric care, to turn attention and focus on clinical care for the elderly, as well as to train staff to promote healthy lifestyles, including physical exercise, regular health check-ups for the elderly, and the management of risk factors for NCDs. Although NCDs are now being prioritized in the health sector, they are not funded at the same level of communicable diseases such as malaria, maternal and child health, and other infectious diseases. Regardless, more concerted effort is required to address the health inequity gaps for both the elderly and NCDs, through generating better media messages, enforcing legislation, using leverages such as pricing, and above all, pursuing coordinated multi sectorial initiatives.

Packages of care (combinations of treatments) for dementia have been proposed to attain optimum outcomes in improving and managing the condition (Prince et al., 2009). The primary goals of managing dementia in health care are: detection and early diagnosis through dissemination of information about the condition; optimization of physical health, cognition activity, and wellbeing through regular physical assessments and cognitive stimulation interventions; detection and treatment of BPSD through dissemination of information and pharmacological treatments; and the provision of information and long term support for carers (Prince et al., 2009). According to Alzheimer's Disease International, the minimum actions recommended for dementia care include: 1) provision of treatment in primary care; 2) ensuring availability of appropriate treatment; 3) giving care in the community; 4) public education about the condition; 5) involving communities, families and consumers in advocating for dementia; 6) established national policies, programmes and legislation for dementia through advocacy and policy briefs; 7) developing appropriate human resource base through training of the health workforce to be able to care for dementia and dementia related illnesses; 8) creating links with other sectors such as non-governmental organizations; 9) establishing systems for monitoring community mental health; and 10) supporting research in dementia. As a LMIC, Ghana has limited resources to implement a comprehensive strategy for curbing the incidence and prevalence of dementia. As the country copes with the challenge of managing the triple burden of disease (communicable diseases, expanding non-communicable diseases as well as injury and trauma), cost effective responses are required to develop and improve dementia care. India, having successfully implemented their national strategy on dementia, would be a good source for Ghana to learn from.

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Appendices

Appendix A: Ethical Review I

(i) Kings College, London

Naana Agyeman

Centre for Global Mental Health

Institute of Psychiatry, Psychology and Neuroscience

King's College London

PO32, David Goldberg Centre

De Crespigny Park

London SE5 8AF

30 March 2015

Dear Naana

PNM/13/14-167 The prevalence and socio-cultural features of dementia among older people in Kintampo, Ghana.

Thank you for submitting a modifications request form for the above study. I am writing to confirm approval of these. The approved modifications are summarised broadly below:

1. Section 4:

    I. Older Person Interview: Removal of physical assessment and replacement of Geriatric Mental State (GMS) with Euro-D scale,

    II. Informant Interview: Removal of DISC-12 Stigma scale.

If you have any queries, please let me know.

Yours sincerely,

James Patterson – Senior Research Ethics Officer

Cc: Maëlenn Guerchet

Appendix B: Ethical Review II

(ii) Kintampo Health Research Centre

Kintampo Health Research Centre (KHRC) Institutional Ethics Committee (IEC)
P.O Box 200
Kintampo, B/A
Ghana, West Africa

Tel: +233(3520)92037 (Ext 117)
E-mail: fred.kanyoke@kintampo-hrc.org

FULL ETHICAL APPROVAL CERTIFICATE

Naana Ama Akyamaa Agyeman
Health Services & Population Research
Institute of Psychiatry, Psychology &
Neuroscience, Kings College,
London, UK

Date: 21st November 2014

Study File Number: 2014-31

Title of study: The prevalence and Socio-Cultural features of Dementia among older people in Kintampo, Ghana

Principal Investigator(s): Naana Ama Akyamaa Agyeman (Ms)

Supervisor(s): Dr. Maelenn Guerchet, Dr. Rosie Mayston, Dr. Seth Owusu-Agyei

Type of Review: Full Board Review

Approval Date: 18th November, 2014

Expiration Date: 18th November, 2015

1. The Kintampo Health Research Centre Institutional Ethics Committee (IEC) is constituted and operates in conformance with requirements of 45 CFR 46, 21 CFR 50, 21 CFR 56 and section 3 of the International Council on Harmonization Guidelines. The OHRP Federal wide Assurance number for the committee is 00011103; the IRB registration number is 0004854.

2. The above study in title was reviewed by the IEC on 18th November, 2014.

3. A full ethical approval was granted for implementation of the study.

4. The following documents were reviewed and approved;
   - 4.1 The prevalence and Socio-Cultural features of Dementia among older people in Kintampo, Ghana, dated 24th October 2014
   - 4.2 Information sheet and Consent form for participants (English and Twi translations)
   - 4.3 Information sheet and Consent form for Informants (English and Twi translations)
   - 4.4 Data collection tools;
   - 4.4.1 Household Questionnaire
   - 4.4.2 Cognitive Test
   - 4.4.3 Geriatric mental State Age CAT Package (GMS [B] 3rd edition)

File number: 2014-31 Page 1 of 2

THE CHAIRMAN, KINTAMPO
HEALTH RESEARCH CENTRE
INSTITUTIONAL ETHICS
COMMITTEE

Kintampo Health Research Centre (KHRC) Institutional Ethics Committee (IEC)
P.O Box 200
Kintampo, B/A
Ghana, West Africa

Tel: +233(3520)92037 (Ext 117)
E-mail: fred.kanyoke@kintampo-hrc.org

4.4.4 Mental State Summary sheet
4.4.5 Socio-demographic and risk factor questionnaire (Participant version)
4.4.6 Informant Questionnaire
4.4.7 Socio-demographic and risk factor questionnaire (Informant version)
4.4.8 Discrimination and Stigma Scale (DISC-12), Version 22/04/09
4.5 Study Budget
4.6 Curriculum Vitae of Principal Investigator

5. During study implementation, the IEC must be informed within 48 hours by the principal investigator (PI) of learning of any (a) unexpected, serious, study related adverse events; (b) disclosed adverse events, or (c) unanticipated problems with the study which may pose risk to study participants or others.

6. Changes or modifications to this research activity must be submitted and approved by the IEC before they are implemented.

7. PI(s) would be required to submit application for renewal of this approval certificate (if necessary) plus a progress report.

8. PI(s) is required to notify the IEC of study completion (end of data collection/last follow-up) or early termination of the research project.

9. Submit final report of the study one month after approval certificate expires (study closure)

10. Before conduct of the study, submit original/final copy of your informed consent forms for an **authentication stamp** before making photocopies for your consent process.

11. Regulated study records, including IEC approvals and signed consent forms, must be securely maintained by PI(s) and available for audits for three years after the study is closed with the IEC.

Sincerely,

THE CHAIRMAN, KINTAMPO
HEALTH RESEARCH CENTRE
INSTITUTIONAL ETHICS
COMMITTEE

Nana Franklin Fei
(Voting member)
For: Chair
Institutional Ethics Committee
Kintampo Health Research Centre

File number: 2014-31

Appendix C: Information sheet

INFORMATION SHEET FOR HOUSEHOLD/PARTICIPANTS

ANOYIFOƆ AMANNEƐBƆ KRATAA

King's College Research Ethics Committee Ref: ***PNM/13/14-167***

Kintampo Health Research Ethics Committee Ref: ***2014-31***

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

WO NSA BƐKA SAA AMANNEƐBƆ KRATAA YI BI

Title: THE PREVALENCE AND SOCIO-CULTURAL FEATURES OF DEMENTIA AMONG OLDER PEOPLE IN KINTAMPO, GHANA

Nhwehwɛmu No Din: Awirefire Yadeɛ Ne Ɛho Asetenam/Amammerɛ Mu Nsɛnkyerɛnneɛ A Ɛfa Wɔn A Wɔn Ani Afiri Ho Wɔ Kintampo Wɔ Ghanaman Mu.

We would like to invite you to take part in a study on the prevalence and socio‐cultural features of dementia in the elderly people in the Kintampo Municipality.

Yɛpɛ sɛ sɛ yɛsrɛ wo ma wode wo ho bɛhyɛ nhwehwɛmu dwumadie a ɛfa awirefire yadeɛ ho ne ɛho asetenam/amammerɛ mu nsɛnkyerɛnneɛ a ɛfa wɔn a wɔn ani afiri ho wɔ kintampo Kuropɔn mu.

1. ***What is the purpose of the study?***

Dementia is a word used by doctors to describe problems with memory, concentration and thinking if they become serious enough to affect day to day life. This is a problem that affects older people in particular; around one in ɖɛ of all those aged ɣʃ years and over. It can be caused by several different disease processes, the commonest of which is Alzheimer's disease. We are keen to understand more about dementia, from Ghana, where the problem has been little studied. We hope to find out how common the condition is in this part of Kintampo Municipality and the effect on how we live our lives. We are also interested in finding out more about how dementia is understood and perceived; what the local beliefs about causes and meaning of the condition are. Finally,

we are interested in the impact of psychological and physical health conditions on the arrangements available for the care and support of the older people and whether they are shunned or isolated.

Ɛdeɛn ne nhwehwɛmu yi botaeɛ? Dementia yɛ adwenem sintɔ bi a adɔkotafoɔ kyerɛ sɛ ɛyɛ ɔhaw bi a sɛ ano yɛ den a, ɛmma onipa nkae adeɛ yie, anaa ɔntumi mfa n'adwene nkɔ biribi so na afei, ɛmma ɔntumi nnwene yie na ɛtumi ha ne daadaa abrabɔ. Yei yɛ ɔhaw bi a ɛtaa ka wɔn a wɔn ani afiri pa ara, na woyi nnipa aduonu a wɔadi mfeɛ aduosia num ne akyire biara a, wɔn mu baako wɔ saa ɔhaw yi bi. Ɛnam nyarewa bebree so na ɛba na deɛ yɛtaa hunu no, ɛne Alzheimer yadeɛ. Yɛde asi yɛn ani so sɛ yɛbɛhwehwɛ saa ɔhaw yi a ɛwɔ Ghana no mu ahunu mu yie ɛsiane sɛ nhwehwɛmu kakra bi pɛ na akɔ so wɔ ho. Yɛn ani da kwan sɛ yɛbɛhunu sɛdeɛ tebea yi teɛ wɔ Kintampo Kuropɔn yi mu na yɛhunu sɛdeɛ ɛho nsunsuansoɔ teɛ wɔ yɛn abrabɔ so. Yɛn ani nso gye ho sɛ yɛbɛhunu sɛdeɛ ɔmanfoɔ nteaseɛ wɔ awirefire yadeɛ yi ho teɛ ɛne sɛdeɛ wɔhunu yadeɛ yi; yɛpɛ sɛ yɛhunu mpɔtam hafoɔ no gyedie fa yadeɛ no farebae ho ne sɛdeɛ wɔsi te yadeɛ no ase fa. Ne korakora no, yɛpɛ sɛ yɛhunu sɛdeɛ ɛho nsunsuansoɔ teɛ wɔ adwenem ne apɔmuden so fa nhyehyɛɛ a wɔayɛ wɔ ayarehwɛ ne mmoa a ɛwɔ hɔ ma wɔn a wɔn ani afiri no ho, na yɛhunu sɛ ɛyɛ adeɛ a wɔayi wɔn totwene anaa nnipa nkɔ wɔn nkyɛn.

2. Why have I been invited to take part?

We are hoping to include about ãɛɛ people all aged ãɛ years and over, living in the Kintampo Municipality and its subɔdistricts. All older residents will be invited to take part and we are trying to contact everyone of such person via the Kintampo Health Research Centre in the Municipality. That is why you have been invited.

Adɛn nti na yɛato nsa afrɛ me sɛ memfa me ho mmɛhyɛ dwumadie yi mu?

Yɛn ani da kwan sɛ yɛbɛnya nnipa ahanson a wɔn nyinaa adi mfeɛ aduoson ne akyire a wɔwɔ Kintampo Kuropɔn yi mu ne nkuro nketewa a atwa ho ahyia mu. Yɛbɛto nsa afrɛ nnipa a wɔn ani afiri no nyinaa ma wɔde wɔn ho ahyɛ mu na yɛrebɔ mmɔden sɛ yɛbɛma Kintampo Apɔmuden Adwuma no ato nsa afrɛ saa nnipa yi nyinaa wɔ Kuropɔn yi mu. Yei nti na yɛato nsa afrɛ wo.

3. *What will happen to me if I take part?*

A researcher will visit you in your own home, at a time that you arrange to suit your convenience. The researcher will have questions to ask about your health and general circumstances, and about experiences in your life up till now.

This will take about õɛ minutes Õi.e. hour and a halfƐ. Then the researcher will

check your height, weight, and blood pressure. This will also take ɛf minutes. We will also ask you to identify for us a family member or friend, who knows you and your current circumstances well. The researcher will also have some questions for them, and this interview will last between ɛf and fɛ minutes. The reason for this interview is that sometimes it helps to have another person's view of how an older person has been coping and about any changes in their health.

Sɛ mede me ho hyɛ mu a, ɛdeɛn na ɛbɛsie?

Onipa a ɔreyɛ nhwehwɛmu no bɛba wo fie wɔ berɛ a wopene so sɛ ɛyɛ ma wo. Ɔbɛbisa wo nsɛm afa w'apɔmuden ne w'asetenam nsɛm nyinaa ho, ɛne osuahunu a woanya wɔ w'abrabɔ mu de bɛsi nnɛ. Nkɔmmɔdie no bɛdi bɛyɛ simma aduokron/ kyerɛ sɛ dɔnhwere baako ne fa. Afei, nhwehwɛmufoɔ no bɛhwɛ wo tenten, wo mu duru ɛne sɛdeɛ wo mogya pem so wɔ wo mu. Yei nso bɛdi simma dunum. Yɛbɛbisa wo ama woakyerɛ yɛn obusuani anaa adamfoɔ a ɔnim wo yie ɛne tebea a wowɔ mu seesei nso yie. Nsɛmmisafoɔ no bɛbisa ɔno nso nsɛm na saa nkɔmmɔdie no bɛdi bɛyɛ simma dunum dekɔ aduonum. Deɛ nti a ɛsɛ sɛ yɛbisa onipa foforɔ nsɛm no ne sɛ ɛtɔ da bi a, na ɛho hia sɛ yɛnya onipa foforɔ adwenekyerɛ fa sɛdeɛ obi a n'ani afiri tumi tena ɛne nsakraeɛ a ɛkɔ so wɔ ne nipadua mu no ho.

3. What are the possible risks of taking part?

There are no inherent risks in participating in the study. The participants will not be given direct incentive of cash or kind. But will be made aware of the inherent benefits to be gained from this study. For example the usefulness of their contribution in collating evidence based data for health planning and programming in the Municipality and country as a whole.

Ɔhaw bɛn na ɛbɛtumi aba wɔ berɛ a mede ho ahyɛ mu? Ɔhaw biara nni hɔ wɔ berɛ a wode wo ho ahyɛ dwumadie no mu. Ɛnyɛ adeɛ a anoyifoɔ no ankasa bɛnya nkuranhyɛdeɛ bi te sɛ sika anaa akyɛdeɛ. Na yɛbɛma moahunu mfasoɔ a ɛwɔ saa nhwehwɛmu yi mu. Mfasoɔ no bi ne sɛ, mmuaeɛ a yɛbɛnya no bɛboa ama yɛanya nsɛm a ɛbɛdi adanseɛ a ɛbɛboa wɔ apɔmuden ho ntotoeɛ ne nhyehyɛɛ mu wɔ Kuropɔn yi ne ɔman yi afanan nyinaa mu.

4. *What are the possible benefits of taking part?*

The people being asked to take part in this study may have dementia and others may have a relative affected. Noõone, either people with an illness or those without can expect any personal benefit from being in the study. We hope that your participation in the research may lead to useful developments for health planning and programming for people with dementia in the Municipality and country as a whole in the future.

Mfasoɔ bɛn na ɛwɔ so sɛ wode wo ho bɛhyɛ dwumadie yi mu?

Nnipa no a yɛne wɔn bɛtwetwe nkɔmmɔ no wɔ awirefire yadeɛ yi, ebi nso abusuafoɔ anya bi. Na obiara nni hɔ a ɔbɛnya mfasoɔ bi afiri hyɛ a ɔde ne ho bɛhyɛ nhwehwɛmu yi mu, sɛ ɛyɛ wɔn a wɔwɔ yadeɛ bi anaa wɔn a wɔnni yadeɛ biara. Yɛwɔ awerɛhyɛm sɛ hyɛ a wode wo ho bɛhyɛ nhwehwɛmu yi mu no de anammɔntuo papa bɛba a ɛbɛboa wɔn a wɔwɔ awirefire yadeɛ yi wɔ Kuropɔn yi ne ɔman yi mu nyinaa daakye.

5. ***Will my taking part be kept confidential?***

All information we collect from you will remain entirely confidential during and throughout the study, and we will not disclose any information to anyone without your permission.

Me ho a mede bɛhyɛ dwumadie yi mu no bɛyɛ kɔkoamsɛm? Nsɛm a yɛn nsa bɛka wɔ nhwehwɛmu yi mu nyinaa bɛyɛ kɔkoamsɛm na ɛnyɛ adeɛ ɛ yɛka akyerɛ onipa foforɔ wɔ berɛ a wommaa ho kwan.

6. ***How is the project being funded?***

Sources of funding for this PhD research will be from Ghana and King's College London in the UK.

Kwan bɛn so na dwumadie yi ho sikasɛm bɛkɔ so? Baabi a sika bɛfiri aba de abɔ saa PhD nhwehwɛmu yi ho bra ne Ghana ɛnna King's College London wɔ UK.

7. ***What will happen to the results of the study?***

To ensure anonymity of responses numbers will be assigned to questionnaires and transcriptions. Only the research team will have access to the data. In the course of dissemination of information, through briefing, presentations, reports and publications participants' names will not be mentioned. We also have the approval of the Ethical Review Board that helps protect your rights during this research project.

Kwan bɛn na wɔde nhwehwɛmu yi ho nsunsuansoɔ no bɛfa so? Sɛdeɛ ɛbɛyɛ na mmuaeɛ a yɛn nsa aka no bɛyɛ kɔkoamsɛm nti, yɛbɛtwerɛ nɔma ama nsɛmmisa ne mmuaeɛ no nyinaa. Wɔn a wɔreyɛ nhwehwɛmu no nko ara na wɔbɛhunu mmuaeɛ no. Berɛ a yɛde nhwehwɛmu yi ho nsunsuansoɔ reto dwa wɔ kwan biara so no, ɛnyɛ adeɛ a yɛbɛbɔ anoyifoɔ no mu biara din wɔ mu. Afei nso, Nhyehyɛɛpa Ho Badwa no nso ama yɛn ho kwan a ɛbɛma yɛatumi abɔ wo kyɛfa ho ban wɔ saa nhwehwɛmu dwumadie yi mu.

8. ***Who should I contact for further information?***

If you have any questions or require more information about this study, please contact me using the following contact details:

Hwan na sɛ mepɛ nsɛm foforɔ bio a menkɔhunu no? Sɛ wowɔ nsɛmmisa bi anaa wopɛ nsɛm foforɔ bio fa saa nhwehwɛmu yi ho a, mesrɛ wo fa kwan a ɛdidi soɔ yi so bɛhunu me:

Naana A. A. Agyeman Kintampo Health Research Centre P. O. Box 200 Kintampo, Ghana

Naana A. A. Agyeman King's College London Institute of Psychiatry David Goldberg Centre Health Services & Population Research Department P. O. Box 029 De Crespigny Park London SE5 8AF Tel: +44 (0) 207 848 5067

9. ***What if I have further questions, or if something go wrong?***

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

Na sɛ mewɔ nsɛmmisa bio, anaa sɛ biribi kɔ kyew a nso ɛ?

Sɛ saa nhwehwɛmu yi ha wo wɔ kwan bi so anaa sɛ wowɔ soboɔ bi bɔ fa sɛdeɛ nhwehwɛmu yi kɔɔ so no ho a, wobɛtumi afa kwan a ɛdidi soɔ yi so akɔhunu King's College London ama wo nsa aka afotuo ne amanneɛbɔ biara a wopɛ:

Kintampo Health Research Centre P. O. Box ɖɛɛ Kintampo, Ghana Director: seth.owusu-agyei@kintampo-hrc.org

Some important points to note:

King's College London Institute of Psychiatry David Goldberg Centre

Health Services and Population Research Department De Crespigny Park London SE5 8AF Tel. of Supervisor (Dr. M. Guerchet): +44 20 7848 0906

☐ Taking part in this study is entirely voluntary

☐ It is for YOU to choose whether or not to take part

☐ You can withdraw at any stage, without having to give a reason for doing so Nsɛnhia bi a ɛsɛ sɛ wohyɛ no nso:

- Ɛnyɛ ɔhyɛ sɛ wode wo ho bɛhyɛ saa nhwehwɛmu yi mu

- Ɛyɛ WOARA wo pɛ sɛ wode wo ho bɛhyɛ mu anaa womfa nhyɛ mu

Wobɛtumi atwe wo ho afiri mu wɔ berɛ biara a wopɛ a wonkyerɛ sɛnti If you agree to take part, please complete the consent form, answering all the questions Sɛ wopene so sɛ wode wo ho bɛhyɛ mu a, mesrɛ wo yiyi nsɛmmisa a ɛwɔ mpenesoɔ krataa yi so no nyinaa ano. **Thank you for reading this information sheet and for considering taking part in this research.** Yɛda wo ase sɛ woakenkan saa amanneɛbɔ krataa yi na woapene so sɛ wode wo ho bɛhyɛ saa nhwehwɛmu dwumadie yi mu.

Appendix D: Consent form I

KING'S College LONDON

CONSENT FORM FOR INFORMANT IN RESEARCH STUDY

ANOYIFOƆ MPENESOƆ KRATAA WƆ NHWEHWƐMU DWUMADIE MU

TITLE OF STUDY: The Prevalence and **Socio-cultural** Features of Dementia among Older People in Kintampo, Ghana

NHWEHWƐ MU NO DIN: Awirefire yadeɛ ne ɛho Asetenam/Amammerɛ mu nsɛnkyrerɛnneɛ a ɛfa wɔn a wɔn ani afiri ho wɔ Kintampo wɔ Ghanaman mu.

Have you read and understood the Study Information Sheet? Woakenkan ate nhwehwɛmu ho amanneɛbɔ krataa yi ase? YES Aane / NO Daabi

Have you had an opportunity to ask questions and discuss the study? Woanya kwan abisa nhwehwɛmu yi ho nsɛm asane adi ho nkɔmmɔ? YES Aane / NO Daabi

Have you received satisfactory answers to all your questions? Wonsa aka mmuaeɛ a ɛtɔ asom wɔ wo nsɛmmisa nyinaa ho? YES Anaa / NO Daabi

Who have you spoken to? Hwan na wo ne no akasa?.....

Do you understand that you are free to with draw from the study:

Wote aseɛ sɛ wobɛtumi atwe wo ho afiri nhwehwɛmu yi mu:

* at any time? Wɔ berɛ biara mu?

* without having to give a reason?

Wɔ berɛ a womma nnyinasoɔ biara? YES Aane/ NO Daabi

DO YOU AGREE TO TAKE PART IN THIS STUDY?

WOPENE SO SƐ WODE WO HO BƐHYƐ SAA NHWEHWƐMU YI MU? YES AANE / NO DAABI

PLEASE NOTE: Your refusal to take part in or your withdrawal from the study at any time will in no way interfere with your normal medical care or that of

your relative or friend.

MESRƐ WO HYƐ NO NSO: SƐ WODE WO HO HYƐ NHWEHWƐMU YI MU ANAA WOTWE WO HO FIRI MU WƆ BERƐ BIARA MU MPO A, ƐNYƐ ADEƐ A ƐBƐHA AYAREHWƐ A WONYA NO DAA NO ANAA DEƐ WO BUSUANI ANAA W'ADAMFO BI NYA NO WƆ KWAN BIARA SO.

_____	_____	_____
Name of Informant	**Date**	**Signature**
(Ɔnoyifoɔ no Din)	(Deeti)	(Signakya)

Thumb Print (Kokurobetie):

_____	_____	_____
Name of Witness	**Date**	**Signature**
(Danseni no Din)	(Deeti)	(Signakya)

_____	_____	_____
Name of Researcher	**Date**	**Signature**
(Nhwehwɛmufoɔ no Din)	(Deeti)	(Signakya)

(Respondent to retain a copy of signed consent)

Name of local investigator: Naana A. A. Agyeman Contact telephone number of local investigator: +**233 (0) 0504518170**

Contact address of local investigator: Kintampo Health Research Centre/King's College London

Name and address of local institution: Kintampo Health Research Centre, P. O. Box **200,** Ghana.

Appendix E: Consent form II

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDY

ANOYIFOƆ MPENESOƆ KRATAA WƆ NHWEHWƐMU DWUMADIE MU

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research

Mesrɛ wo, yi krataa yi so nsɛmmisa no ano wɔ berɛ a woakenkan amanneɛbɔ krataa no awie/ woatie nhwehwɛmu no mu nkyerɛkyerɛmu awie.

Title of Study: ***THE PREVALENCE AND SOCIO-CULTURAL FEATURES OF DEMENTIA AMONG OLDER PEOPLE IN KINTAMPO, GHANA***

Nhwehwɛmu No Din: AWIREFIRE YADEƐ NE ƐHO ASETENAM/AMAMMERƐ MU NSƐNKYRERƐNNEƐ A ƐFA WƆN A WƆN ANI AFIRI HO WƆ KINTAMPO WƆ GHANAMAN MU.

King's College Research Ethics Committee Ref: PNM/13/14-167

Kintampo Health Research Centre Institutional Ethics Committee Ref: 2014-31

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Yɛda wo ase sɛ woadwene ho sɛ wode wo ho bɛhyɛ nhwehwɛmu dwumadie yi mu. Ɛsɛ sɛ onipa a ɔreyɛ nhwehwɛmu no kyerɛkyerɛ dwumadie yi mu kyerɛ wo ansa na woapene so sɛ wode wo ho bɛhyɛ mu. Sɛ wowɔ nsɛmmisa bi fa Amanneɛbɔ Krataa no ho anaa nkyerɛkyerɛmu a wɔde ama wo dada no ho a, mesrɛ wo bisa nhwehwɛmufoɔ no ansa na woasi gyinaeɛ sɛ wode wo ho bɛhyɛ mu. Yɛbɛma wo Mpenesoɔ Krataa yi bi na wode ato hɔ ahwɛ so berɛ biara a ɛho bɛhia.

I agree to be re-contacted by the researcher for a second part of in-depth interview -

Mepene so sɛ nhwehwɛmufoɔ no bɛsane aba me nkyɛn bio abɛbisa me nsɛm a emu dɔ.

Yes / No – if **Yes** state which form of recontact please: Aane/ Daabi, sɛ Aane a, mesrɛ

wo kyerɛ kwan a ɔnsane mfa so ne wo

Ntwetwe nkɛmmɔ:

Door to door (agree on convenient day/time) ɔmmra me fie/pene berɛ anaa da a ɛyɛ

Telephone (request for number) ahomatromfoɔ so

Respondent preference (to be agreed upon) deɛ ɔnoyifoɔ no pɛ

I confirm that I have read and understood the information sheet dated ..... for the above study. I have had the opportunity to consider the information and asked questions, which have been answered satisfactorily.

Megye tom sɛ makenkan amanneɛbɔ krataa a deeti a ɛwɔ so ne..... a ɛfa saa nhwehwɛmu yi ho no ate aseɛ yie. Manya kwan asusu nsɛm no ho na mabisa nsɛm biara a ɛhia anya anoyie a ɛtɔ asom.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

Mete aseɛ sɛ ɛnam ɔpɛpa so na mede me ho ahyɛ dwumadie yi mu na mewɔ ho kwan sɛ mɛtumi atwe me ho afiri dwumadie yi mu a menkyerɛ sɛnti.

I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of handling data of these institutions:

i. **King's College Research Ethics Committee**
ii. **Kintampo Health Research Centre Institutional Ethics Committee**

Mepene so sɛ wɔbɛgye me ho nsɛm de adi dwuma a wɔakyerɛ mu akyerɛ me yi. Mete aseɛ sɛ wɔde me ho nsɛm no bɛdi dwuma no sɛdeɛ yɛ yɛ no wɔ adwuma kuo te seɛ:

i. **King's College Research Ethics Committee**
ii. **Kintampo Health Research Centre Institutional Ethics Committee**

I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes.

Mete aseɛ sɛ nnipa bi a wɔnim de a wɔfiri Kɔlegyi no mu bɛyɛ nsɛm a mɛka no mu nsakraeɛ de adi dwuma a wɔahyehyɛ no.

I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.

Mete aseɛ sɛ wɔde kɔkoamsɛm ho nhyehyɛɛ bɛdi dwuma na ɛnyɛ adeɛ a ɛbɛba sɛ obi bɛhunu sɛ ɛyɛ me wɔ nwoma biara mu.

Anonymity is optional for this research. Please select from the following 3 options:

a. I agree to be fully identified
b. I agree to be partially identified
c. I wish to remain anonymous

Saa nhwehwɛmu dwumadie yi, yɛnnfa obi ho nsɛm ne ne din nnto dwa aberɛ a yɛne no nka ho asɛm.

a. Mepene so sɛ monfa me ho nsɛm me ho nsɛm ne medin nto dwa.
b. Mepene so sɛ monfa me ho nsɛm ne medin nto dwa.
c. Menpene so sɛ mo de me din ne meho nsɛm bɛto dwa koraa

I agree to be contacted in the future by Kintampo Health Centre & King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature.

Megye tom sɛ Kintampo Apɔmuden Adwuma ne King's College London mu nhwehwɛmufoɔ ahodoɔ a wɔpɛ sɛ wɔne me sane toa nhwehwɛmu yi so anaa wɔne me yɛ nhwehwɛmu foforɔ no bɛtumi afrɛ me ama yɛadi saa dwuma no.

I agree that the research team may access my medical records for the purposes of this research project.

Megye tom sɛ wɔn a wɔreyɛ nhwehwɛmu no bɛnya m'apɔmuden ho nsɛm de adi dwuma wɔ saa nhwehwɛmu yi mu.

I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would/would not be identifiable in any report).

Megye tom sɛ wɔn a wɔreyɛ nhwehwɛmu no bɛtumi de me ho nsɛm adi daakye nhwehwɛmu bi ho dwuma na wɔbɛyɛ nsakraeɛ wɔ mu ma nhwehwɛmu ho agyinatukuo agye atom. Ɛba saa a, ɛnyɛ adeɛ a me ho nsɛm no bɛda no adi sɛ ɛyɛ me.

I understand that the information I have submitted will be published as a report and I wish to receive a copy of it.

Mete aseɛ sɛ wɔbɛtintim nsɛm a maka no wɔ nwoma mu na mɛpɛ sɛ mɛnya bi.

I consent to my interview being audio/video recorded.

Mepene so sɛ wɔde nsɛmmisa no bɛgu afidie so anaa wɔbɛtwa no video.

I understand that I must not take part if I fall under the exclusion criteria as detailed in the information sheet and explained to me by the researcher.

Mete aseɛ sɛ ɛnyɛ adeɛ a mɛtumi de me ho ahyɛ nhwehwɛmu yi mu wɔ berɛ a ada adi sɛ nhyehyɛɛ a ɛwɔ amanneɛbɔ krataa no mu mma me ho kwan sɛdeɛ

yɛakyerɛ mu akyerɛ me no ara.

I agree that my Doctor may be contacted if any unexpected results are found in relation to my health.

Megye tom sɛ, sɛ nsunsuansoɔ bi a ɛnyɛ ba m'apɔmuden ho a, wɔbɛhwehwɛ me dɔkota akyirikwan.

I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.

Mabɔ onipa a ɔreyɛ nhwehwɛmu no amanneɛ afa nhwehwɛmu bi a mede me ho ahyɛ mu seesei anaa deɛ mede me ho hyɛɛ mu abosome dummienu a atwam no ho.

I agree to maintain the confidentiality of focus group discussions.

Megye tom sɛ mɛdi kɔkoamsɛm nhyehyɛɛ a ɛfa nnipakuo nkutahodie ho no so.

I understand that confidentiality cannot be guaranteed during the teamwork.

Mete aseɛ sɛ kɔkoamsɛm no nhyehyɛɛ no rentumi nyɛ ferenkyemm wɔ berɛ a nnipakuo no redi dwuma.

_____	_____	_____
Name of Participant	**Date**	**Signature**
(Ɔnoyifoɔ no Din)	(Deeti)	(Signakya)

Thumb Print (Kokurobetie):

_____	_____	_____
Name of Witness	**Date**	**Signature**
(Danseni no Din)	(Deeti)	(Signakya)

_____	_____	_____
Name of Researcher	**Date**	**Signature**
(Nhwehwɛmufoɔ no Din)	(Deeti)	(Signakya)

Appendix F: Training manual

Training manual for Field Supervisors

(i) Supervisors guide for Dementia Study KHRC

Aim

i. Investigate dementia in rural Ghana: prevalence, associated factors, experiences of persons living with dementia and that of their caregivers.

Research Questions / Objectives

Research Question

1. What is the prevalence of dementia?
2. What socio-demographic and care related factors are associated with dementia among the elderly population within the KHDSS?

Objectives

iv. Estimate the prevalence of dementia in the study population.

v. Investigate associations between demographic, socio-economic factors, needs for care / disability and dementia.

Research Question

3. What are the experiences of living with dementia in this setting?

Objectives

vi. Explore the beliefs, perception and understanding and ideas of causality of dementia from the perspective of affected older persons and their families.

Research Question

4. How do families of older persons with dementia cope with their condition?

Objectives

vii. Measure carer strain and assess the extent to which this is associated with dementia

viii. Explore aspects of care arrangements for the person living with dementia - (*who cares, what factors influence division of care, how care-related decisions are made, what are the effects on carers, what are the needs for care*)?

Inclusion Criteria

- Older person (male/female) who is 70 years or above
- Verified from the DSS register as resident within catchment area for **study duration**
- Identified, understood information on study, agreed to participate and signed / thumb printed informed consent

Exclusion Criteria

- Not matched from the register
- Verified from the DSS register but moved / deceased
- Identified but declined to participate

Recruitment of Study Participants

The PI and the trained Field Supervisors (interviewers) will visit identified households / index older persons, and explain the study to them. Information sheets and consent forms will be left with them and collected after 24 hours. If they consent to participate they will be invited and time of interviews arranged. They will be informed their household may be selected for a second interview. This will be repeated in all those sampled in the Kintampo Health Demographic Surveillance Site. Participation will be by signed / thumb printed informed consent, or by next of kin agreement if lacking capacity. Participants' ages will be checked at interview (stated and documented age, age according to an informant and event calendars to reconcile discrepancies). Interviews should be conducted in the participant's own home.

Essential elements of the general consent include

(i) The participant is free to decide not to take part.

(ii) There will be no negative consequences of a decision not to take part, particularly for their clinical care.

(iii) If they do decide to take part, they can drop out at any time, without giving reasons.

(iv) The name and contact details of the investigator must be listed on the consent form and the information sheet. A copy of both must be left with the participant, and the local investigators must retain a copy of each.

(v) In the event that the participant does not have the capacity to give informed consent (e.g. dementia), then the information sheet should be read to them in the presence of a family member, who confirms that this has been done, that there was no sign

of dissent from the person with dementia, and that they, the family member agree to the participation of the person with dementia.

(vi) In the event that the participant cannot read or write, they could be asked to thumbprint and an independent person who can read and write witnesses this (if possible).

Data Collection / Instruments

Data collection is based on the 10/66 Protocol procedure using the assessment interviews. These generate information on dementia diagnosis, mental disorders, physical health, anthropometry demographics, an extensive non-communicable disease and dementia risk factor questionnaire, disability and functioning, health service utilisation, care arrangements and caregiver strain. **Data should be collected directly on data coding sheets.** Each interview lasting approximately 2-2½ hours **should be conducted in the homes of the eligible participants who have agreed to participate or the house of a relative/friend of participant's choice. It should be 'A QUIET PLACE'.**

Instruments

Brief description of structured clinical mental state interviews for the elderly persons consist of:

i. The **Household Questionnaire*** collecting contact information and assessing the household composition and its assets

ii. The **Background Socio-demographic and Risk Factors Questionnaire*** (information on age in years, sex, marital status, education, literacy, living circumstances, health, use of services) for both participant and informant.

iii. A **Cognitive Test Battery*** - **a)** the Community Screening Instrument for Dementia (CSI-D) COGSCORE incorporating the CERAD animal naming verbal fluency task and **b)** the modified 10 word list learning tasks with delayed recall; developed especially to be used in low education / different cultures and therefore appropriate for use for study population.

iv. The **Euro_D Scale*** - a structured depression symptom scale, designed for older and derived from the Geriatric Mental State* (GMS AGECAT).

v. An **Informant Interview*** the CSI-D RELSCORE for evidence of cognitive and functional decline; this part of the CSI-D increases the performance of the

instrument (better sensitivity / specificity). An extended informant interview, the History and Aetiology Schedule-Dementia Diagnosis & Subtypes HAS-DDS provides more detailed information on onset and course of possible dementia syndrome.

Economic Impact will be assessed using the Client Service Receipt Inventory for information on type and cost of accommodation, income from all sources, for the person with dementia and their caregiver, the occupation of caregiver, etc.

Practical Impact – contact time between caregiver and cared person, time spent by the caregiver in the last 24hrs in specific care giving activities; communicating, using transport, dressing, eating looking after one's appearance, and supervising

Caregiver Perceived Strain will be appraised with a 22-item Zarit Burden Interview (ZBI)

The **mental health state of caregiver** will be measured with Self-Reporting Questionnaire 20 (SRQ 20)

Behavioural and Psychological Symptoms of Dementia (BPSD) (knowledge and attitudes regarding dementia) will be assessed using informant questionnaire, the Neuropsychiatric Inventory (NPI-Q)

Equipment/ Materials

Paper questionnaires: Each interviewer will be given a single copy of the full assessment (6 sets), translated into the local language, in an arch file and then to code responses on to a data entry form. Data entry forms (**6 sets**) for all questionnaires will be made available for your coding.

Other Equipment: Each interviewer will be given a notepad pencil(s), eraser, sharpener, back pack, an ink pad, a box of match sticks for the 4-Stick design, clip board to clip the entry sheets for easy coding, and raincoats.

Data Collection Advice

Security and confidentiality: The household and participant databases are very important, for these two main reasons

a) Without them, it is very difficult to carry out the baseline survey, and impossible to carry out a follow-up survey

b) They are the key that would link the confidential data collected in the survey to the identities (names and addresses) of particular individuals.

For these reasons, data entry sheets from each Supervisor should be given to the PI at the end of each day to keep them secure under lock and key. Copies of computerised records would be sent via Drop box to Maëlenn Guerchet and Martin Prince at the Institute of Psychiatry, Psychology & Neuroscience.

Age Estimation / Verification

To estimate or verify the ages of participants please consider the following events calendar below:

CALENDAR OF IMPORTANT EVENTS

No.	Event	Date
1.	**The building of the Kintampo Police Station**	**1923**
2.	**The 2nd World II Began**	**1939**
3.	**The 2nd World II Ended**	**1945**
4.	**The Fight between the Mo and the Nafaana**	**1946**
5.	**The Eclipse of the Sun in Ghana**	**1946**
6.	**Ghana's Independence Day**	**1957 (6th March)**
7.	**Dr. Kwame Nkrumah's first visit to Kintampo**	**1957 (28th Oct.)**
8.	**General Mitchel Plane Crash**	**1962**

Who should be selected as the informant/ principal caregiver?

You (interviewer) will not necessarily know, at the time of selecting the informant

a) Whether the participant has dementia

b) Whether the participant is dependent and needs / receives care

Therefore some informants will be caregivers, some will be co-residents or other close contacts with no caring role.

- The informant should be the person who knows the older person best.

- They are likely to be correspond with the older person, but do not have to be, if a non-correspondent is better qualified to be the informant.
- They are likely to be a family member, but again, do not have to be, if a friend or neighbour is better qualified to be the informant.
- Time spent with the older person may be the criteria for deciding the best informant, if there are several correspondent family members.

Where the older person needs care and support, **you should then aim to select** the main caregiver as the informant. The main caregiver may be

a) **The 'organisational caregiver'**, usually a close family member who is responsible for making the arrangements for care, while they may not actually do much direct caring themselves (they may for example work during the day) and

b) **The 'hands on caregiver'**, who is directly responsible for providing the physical care and supervision. The 'hands on caregiver' may be the 'organisational caregiver', or may be another member of the family, or may be a paid caregiver.

In general, **you should not select a paid caregiver** to be the informant; choose the family member who is the main organisational caregiver instead.

Order of the assessments

The questionnaires for the population-based study are administered in this order:

1. **Household questionnaire**

At the outset of the interview, with the household members gathered together, the interviewer ascertains names of contacts to facilitate tracing the participant at a later date, the participant's age, the household composition (who lives there), and some indicators of household wealth.

2. **Assessments for the older participant**

a) Cognitive module (cognitive component of the CSI 'D' plus 10 word list-learning test)

b) Clinical interview – Euro_D Scale

c) Background socio-demographic and risk factor questionnaire (participant version)

3. **Assessments for the informant/ correspondent**

I. Informant interview

a) Background information about informant, administered to all informants

b) Caregiver questionnaire, administered only to informants who are caregivers, that is where the participant is not fully independent

c) The informant section of the CSI'D asking about cognitive and functional decline, is administered to all informants

d) The 'History and Aetiology Schedule – Dementia Diagnosis and Subtype' (HAS-DDS) giving information on onset and course of dementia, is administered only when CSI'D' identifies some cognitive and functional decline with a score of 2 or more.

e) NPI (Behavioral and Psychological Symptoms of Dementia), is administered to all informants

II Background socio-demographic and risk factor questionnaire (informant version), is administered instead of, or in addition to the participant version where the participant is too demented or otherwise unable to answer the questions reliably.

The order of interview for the informant interview is dictated in the interview. Make sure that you apply the skips carefully.

EURO_D SCALE

The EURO_D SCALE is simple and they generally elicit a straightforward, codeable response. Therefore if:

- **No symptom is volunteered – no symptom is coded**
- **If in doubt, code down (symptom not present)**
- **Only one item requires judgment – obvious or excessive guilt**

For each item the interviewer should:

Ask the item just as it is written

If the participant asks for clarification repeat the item

Attempt to code the participant's spontaneous response according to the criteria laid down.

Do not spend too long over this. As soon as you are reasonably sure, code and move on.

If in doubt as to whether the symptom is present (1) or absent (2), code absent (2).

COGNITIVE INTERVIEW

There are two situations where it will be difficult to carry out this section. These are:

Participants may be so demented that they do not understand what is being asked of them, and give more or less random responses to questions.

People with early dementia may show a 'catastrophic' i.e. angry reaction to being tested, for example accusing the interviewer of asking 'stupid questions' or of insulting them. For responses elicited as **'Don't know'/ 'no answer'/ 'incomprehensible or irrelevant answer',** they should all be coded **as a 'failure' for that test.**

Give up at the outset, **only if it is impossible to administer** the tests because of total communication failure as in the Participant being:

Deaf

Mute

Otherwise attempt to administer even if the participant is getting most or all questions badly wrong.

Give up after starting **only if it becomes impossible to continue to administer:**

Severe dementia

Participant anger or discomfort

In principle, we want coding for all questions even if the participant has got all of them wrong.

Data handling / coding sheets

a) Data will be coded by hand, onto data coding sheets. Due to budget constraints and the cost of photocopying we wish to **request that data should not be entered directly on to the questionnaire**.

b) Data would be entered '**as it was collected'**. The principle is to keep this time as short as possible, and not to allow interviews to 'stack up' unentered therefore no minimum time interval between collection and data entry was agreed, but the principle was to keep this time as short as possible, and not to allow interviews to 'stack up' unentered

c) Epidata for data entry will be used, with data entry files provided by the London coordinating centre for this study.

d) Data entry should if possible use the double data entry method in Epidata, to keep data transcription errors to a minimum. This might need a special data entry clerk to be employed.

e) The KHRC and Supervisors/Data Entry Clerks will be provided, as necessary with:

(i) Paper data coding sheets.

(ii) Epidata software.

(iii) Epidata data entry files

f) Data will be transferred, as entered, by e-mail / drop box to the IoPPN, London every month. This will allow for the data to be checked again for consistency, and for any unusual data distributions to be detected as soon as possible. Also, **most importantly** we will be able to back up copies of data to insure against local data loss through software failure, accidental deletion, or failure or theft of computers.

Quality control

This is absolutely critically important. If the data quality is poor, then the study will be meaningless. It is the responsibility of the PI and her Supervisors to ensure that the study protocol is applied properly.

Interviewer supervision

In the early stages of the study, the interviewers would be accompanied as they conduct the fieldwork, to check that each of the elements of the protocol; interviewing and data coding, is being done properly.

Each of the interviewer's scripts will be randomly selected and reviewed regularly for:

a) Completeness

b) Unusual patterns of response

c) High levels of missing data

In the early stage of the study, this will be done routinely for all interviewers, on all interviews. Later, when we are confident that the interviews are going well, this process will be relaxed **slightly**. However, there will **still be a random selection review** of interviews for all interviewers throughout the data collection period to encourage interviewers lagging behind their colleagues.

The PI of this study will regularly run computerised range checks on data as soon as it is entered to check for obvious invalidity problems. Ideally this will be done every 2-4 weeks.

Meetings/Debriefings

The PI of study will **hold weekly meetings with all interviewers to discuss problems** that they may have encountered in the fieldwork. These may be detailed questions on how to code individual items, or more general issues, for example refusals, severe morbidity with unmet needs, negative reactions to the interview etc. It is particularly important to hold these meetings frequently in the early stage of the fieldwork. The frequency can be relaxed later, **but it is important to hold the meetings regularly throughout the fieldwork period. One of the purposes is to keep the interviewers motivated and interested in their work.** Without this, the data quality will certainly suffer.

Organisation:

We will be working as a team. However, if you **encounter any challenge kindly get in touch with the PI (Naana Agyeman-AN) and the Research Officer (Solomon Nyame or Solo-NU).**

Calendar:

Duration of main data collection for the study (the quantitative arm) of the study is six (6) months. It begins (formally) **from 2nd March ends August 2015**. The qualitative arm **will be conducted by only the AN & NU** after two-thirds of the quantitative interviews have been conducted. This might begin in June, and end in September 2015.

Names of the team and codes

NAME	CODE
Naana ***AGYEMAN***	**AN**
Solomon ***NYAME***	**NU**
Joshua ***BUSI***	**JH**
Edward ***OFORI***	**QI**
Henry Kofi ***AMO***	**AK**
Yussif ***WASHIW***	**YW**
Veronica ***FUMEY***	**VF**
Paulina ***WONWAANA***	**WV**

Appendix G: Household Questionnaires (Twi)

10/66 Awirefire Ho Nhwehwɛmu Kuo Nnipa Ho Nsɛm Nhwehwɛmu
ɔpɛpɔn 2015

10/66 Dementia Research Group Population-based study
January 2015

Household Questionnaire
Abusua Kuo/Fidua Mu Nsɛmisa

Administer this questionnaire at the beginning of the interview to the older person with other members of the household present, who may be encouraged also to provide information. Aim for a consensus.

---

1 (AHYƐNSO DEƐ)

ɛda a nkɔmodie yi kɔɔ so:	{DATE}	<dd/mm/yy>
Enter date as day/month/year, e.g.		<05/10/2015>
Nea ɔrebisa nsɛm no ahyɛnso nɔma:	{INTERID}	
Interviewer ID number		
Abusua kuo ahyɛnso nɔma:	{HOUSEID}	
Household ID number		
Obi a ɔka dwumadie yi ho ahyɛnso nɔma:	{PARTICID}	
Participant ID number		

---

1 Nnipa Akyirikwan/Contacts

Sɛdeɛ ɛbɛyɛ na yɛbɛtumi ahuhu ɔnoyifoɔ no akyirikwan daakye bi nti, gye nnipa baanu foforɔ bi din ne wɔn akyirikwan ha ho. ɛsɛ sɛ yɛtumi kɔ so ne nnipa baanu yi di nkutaho wɔ berɛ a onipa a n'ani afiri no atu afiri efie ha. ɛsɛ sɛ saa nnipa yi yɛ wɔn a wɔnim onipa a n'ani afiri no abusua yie nanso wɔte baabi foforɔ a ɛnyɛ baabi a ɔnoyifoɔ no teɛ.

(Ɛbɛtumi mpo aba sɛ ɔnoyifoɔ no ne n'abusuafoɔ no nyinaa bɛtumi atu afiri efie hɔ) .

1.1 First Contact Person

Name {contna1}
_____

Address 1 {contad11}
_____

Address 2 {contad21}
_____

City/ Town/ Village {contct1}
_____

{Phone11}_____ {phone12}_____

1.2 Second Contact Person

Name {contna2}
_____

Address1 {contad12}
_____

Address2 {contad22}
_____

City/ Town/ Village {contct2}
_____

{Phone21}_____ {phone22}_____

Anonymity is optional for this research. Please select from the following 3 options:

d. I agree to be fully identified
e. I agree to be partially identified
f. I wish to remain anonymous

Saa nhwehwɛmu dwumadie yi, yɛnnfa obi ho nsɛm ne ne din nnto dwa aberɛ a yɛne no nka ho asɛm.

d. Mepene so sɛ monfa me ho nsɛm me ho nsɛm ne medin nto dwa.
e. Mepene so sɛ monfa me ho nsɛm ne medin nto dwa.
f. Menpene so sɛ mo de me din ne meho nsɛm bɛto dwa koraa

I agree to be contacted in the future by Kintampo Health Centre & King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature.

Megye tom sɛ Kintampo Apɔmuden Adwuma ne King's College London mu nhwehwɛmufoɔ ahodoɔ a wɔpɛ sɛ wɔne me sane toa nhwehwɛmu yi so anaa wɔne me yɛ nhwehwɛmu foforɔ no bɛtumi afrɛ me ama yɛadi saa dwuma no.

I agree that the research team may access my medical records for the purposes of this research project.

Megye tom sɛ wɔn a wɔreyɛ nhwehwɛmu no bɛnya m'apɔmuden ho nsɛm de adi dwuma wɔ saa nhwehwɛmu yi mu.

I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would/would not be identifiable in any report).

Megye tom sɛ wɔn a wɔreyɛ nhwehwɛmu no bɛtumi de me ho nsɛm adi daakye nhwehwɛmu bi ho dwuma na wɔbɛyɛ nsakraeɛ wɔ mu ma nhwehwɛmu ho agyinatukuo agye atom. Ɛba saa a, ɛnyɛ adeɛ a me ho nsɛm no bɛda no adi sɛ ɛyɛ me.

I understand that the information I have submitted will be published as a report and I wish to receive a copy of it.

Mete aseɛ sɛ wɔbɛtintim nsɛm a maka no wɔ nwoma mu na mɛpɛ sɛ mɛnya bi.

I consent to my interview being audio/video recorded.

Mepene so sɛ wɔde nsɛmmisa no bɛgu afidie so anaa wɔbɛtwa no video.

I understand that I must not take part if I fall under the exclusion criteria as detailed in the information sheet and explained to me by the researcher.

Mete aseɛ sɛ ɛnyɛ adeɛ a mɛtumi de me ho ahyɛ nhwehwɛmu yi mu wɔ berɛ a ada adi sɛ nhyehyɛɛ a ɛwɔ amanneɛbɔ krataa no mu mma me ho kwan sɛdeɛ

yɛakyerɛ mu akyerɛ me no ara.

I agree that my Doctor may be contacted if any unexpected results are found in relation to my health.

Megye tom sɛ, sɛ nsunsuansoɔ bi a ɛnyɛ ba m'apɔmuden ho a, wɔbɛhwehwɛ me dɔkota akyirikwan.

I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.

Mabɔ onipa a ɔreyɛ nhwehwɛmu no amanneɛ afa nhwehwɛmu bi a mede me ho ahyɛ mu seesei anaa deɛ mede me ho hyɛɛ mu abosome dummienu a atwam no ho.

I agree to maintain the confidentiality of focus group discussions.

Megye tom sɛ mɛdi kɔkoamsɛm nhyehyɛɛ a ɛfa nnipakuo nkutahodie ho no so.

I understand that confidentiality cannot be guaranteed during the teamwork.

Mete aseɛ sɛ kɔkoamsɛm no nhyehyɛɛ no rentumi nyɛ ferenkyemm wɔ berɛ a nnipakuo no redi dwuma.

Name of Participant	**Date**	**Signature**
(Ɔnoyifoɔ no Din)	(Deeti)	(Signakya)

Thumb Print (Kokurobetie):

_____	_____	_____
Name of Witness	**Date**	**Signature**
(Danseni no Din)	(Deeti)	(Signakya)

_____	_____	_____
Name of Researcher	**Date**	**Signature**
(Nhwehwɛmufoɔ no Din)	(Deeti)	(Signakya)

Appendix H: Cognitive Test Questionnaire (Twi)

10/66 Awirefire Ho Nhwehwɛmu Kuo Nnipa Ho Nsɛm Nhwehwɛmu ɔpɛpɔn 2015

10/66 Dementia Research Group Population-based study January 2015

COGNITIVE TEST

1.: IDENTIFICATION (AHYƐNSO DEƐ)

1.1: Ɛda a nkɔmodie yi kɔɔ so: {DATE}
<dd/mm/yy>
Enter date as day/month/year, e.g.
<05/10/2015>

1.2: Nea ɔrebisa nsɛm no ahyɛnsoɔ nɔma: {INTERID}
Interviewer ID number

1.3: Abusua kuo ahyɛnsoɔ nɔma: {HOUSEID}
Household ID number

1.4: Obi a ɔka dwumadie yi ho ahyɛnsoɔ nɔma: {PARTICID}
Participant ID number

NSƐM BI A YAHYEHYƐ ADESUA

Mere bɛkenkan nsɛm bi a yahyehyɛ. Me pawokyɛw tie no yie ɛfiri sɛ, sɛ mekenkan wie a mɛma wo abobɔ saa nsɛm no so de akyerɛ me. Saa nsɛm no wɔ krataa yi so.

Kenkan nsɛm du no na ɛyɛ twetwe emu kakra kakra. Hyehyɛ nea ɔbɛtumi abobɔ no yie no wɔ saa krataa yi so.

		1ST	2ND	3RD		
Nkwan	(Soup)				Soup	(Nkwan)
Abasa	(Arm)				Arm	(Abasa)
Krataa	(Letter)				Letter	(Krataa)
Ɔhemaa	(Queen)				Queen	(Ɔhemaa)
Tekiti	(Ticket)				Ticket	(Tekiti)
Ɛserɛ	(Grass)				Grass	(Ɛserɛ)
Abrannaa	(Veranda)				Veranda	(Abranaa)
Boɔ	(Stone)				Stone	(Boɔ)
Nkrantɛ	(Cutlass)				Cutlass	(Nkrantɛ)
Abaa	(Stick)				Stick	(Abaa)
Dodoɔ Aba	**(Total)**				Total	(Dodoɔ Aba)

Ɛdikan:

1. {LEARN1} ##

Afei bobɔ nsɛm no nea wokae nyinaa ma me.

(Interviewer – Score total number of words correctly recalled)

Ɛtɔso mienu:

Meda wase. Mesan akenkan nsɛm no bio. Ɛbio no tie no yie ɛfiri sɛ mɛma wo asan abobɔ nsɛm no so bio sɛ me wie a.

(Interviewer – Read out the ten words, pausing for one second between each)

2. {LEARN2} ##

Afei bobɔ nsɛm no nea wokae nyinaa kyerɛ me.

(Interviewer – Score total number of words correctly recalled)

Meda wase. Mesan akenkan nsɛm no nea etwa toɔ. Ɛbio, tie no yie efiri sɛ mesan ama wo abobɔ nsɛm no so bio sɛ me wie a.

3. {LEARN3} ##

Afei bobɔ nsɛm no nea wokae nyinaa kyerɛ me.

(Interviewer – Score total number of words correctly recalled)

The Community Screening Instrument for Dementia (CSI-D)

4. {NAME} **##**

Mepɛ sɛ wo kae me din. Me din a ɛtwa toɔ de (xxxx). Mepa wokyɛw bɔ na mentie.

Cannot repeat name 0
Successfully repeats name 1

Yɛbɛ hyɛ aseɛ abobɔ ɛneɛma din. Mede me nsa bɛkyerɛ biribi so na mɛpɛ sɛ wobɛbɔ adekorɔ din. Te sɛ (Show pencil)

5. {PENCIL} PƐNSERE (Interviewer shows pencil)

Ɛdeɛn nie/Yɛfrɛ wei sɛn?

Incorrect 0
Correct 1

6. {WATCH} WƆKYE

Interviewer points to their Watch

Incorrect 0
Correct 1

7. {CHAIR} AKONDWA

Interviewer pats Chair

Incorrect 0
Correct 1

8. {SHOES} / {SOCKS} ƐMPABOA / SƆKESE

Interviewer points to their Shoes / Socks

Incorrect 0
Correct 1

9. {FINGER NAIL} NSA MMƆWERƐ

Interviewer points to their Finger Nail

Incorrect 0
Correct 1

10. {ELBOW} ABATWƐ
Interviewer points to their Elbow

Incorrect 0
Correct 1

11. {SHOULDER} ABATI
Interviewer points to their Elbow

Incorrect 0
Correct 1

Seisei ara mekyerɛɛ ɛneɛma bi na wo bobɔɔ din. Afei mebɔ adeɛ bi din na wakyerɛ sɛ nea adeɛ no teɛ

12. (BRIDGE) (NSAMSOƆ)
What is a bridge? Nsamsoɔ yɛ deɛbɛn**? (Bibi a ɛtwere nsuo anaa amena a lɔre anaa nipa faso)**?

Incorrect 0
Correct 1

13. (Hammersley & Atkinson) ABƆSOBAA
Yɛde hammer / abɔsobaa yɛ dɛn? (**Kapintafoɔ de bɔ dadewa so**)

Incorrect 0
Correct 1

14. {PRAY}/MPAEBƆ
Nipa kɔ kɔyɛ deɛn wɔ asɔre anaa nkramo dan mu? (**Wɔ kɔbɔ mpayeɛ/Wɔkɔyɛ ayeforɔ etc**)

Incorrect 0
Correct 1

15. {CHEMIST} ADURO ADETƆNDAN

Ɛhen na mo yare a, mo kɔtɔ aduro? Baabi a yɛtɔn nnuro tesɛ **Drugstore, Chemist, Pharmacy** etc

Incorrect 0
Correct 1

16. {REPEAT} KA DI MAKYE

Seisei mɛpɛ sɛ neɛ me bɛka yi wo bɛka adi makyi pɛɛpɛ. (Only one presentation is allowed, so the interviewer must read the phrase clearly and slowly enunciating carefully). (Exact phrase only)

'Mekɔ borɔdeɛ ase, borɔdeɛ ase kɔɔ'

Incorrect	0
Correct	1

WORD LIST LEARNING – Delayed recall

Wokae sɛ mekenkan nsɛm bi a na ɛwɔ krataa so no? Emu dodoɔ sɛn na wokae seeisei. Wobɛtumi abobɔ nea wokae nyinaa so akyerɛ me?

Nkwan (SOUP)	
Abasa (ARM)	
Krataa (LETTER)	
ɔhemaa (QUEEN)	
Tekiti (TICKET)	
ɛserɛ (GRASS)	
Abrandaa (VERANDA)	
Boɔ (STONE)	
Nkrantɛ (CUTLASS)	
Abaa (STICK)	
Dodoɔ Aba (TOTAL SCORE)	

17. (RECALL) Total number of words correctly recalled

18. {NRECALL}
Wokae me din/Wokae me din a mebɔ kyerɛ wono? Mede sɛn?

Incorrect 0
Correct 1

(Allow minor errors)

19. Afei yɛrebɛyɛ biribi a ɛyɛ sononko kakra. Merebɛka asɛm baako bi a ɛtumi agyina hɔ ma nsɛm bebree; na mepɛ sɛ sɛ mebɔ asɛm no din a wo nso wobobɔ nsɛm dodoɔ a wodwene sɛ ɛne saa asɛm no na ɛbɔ. Sɛ ebia, sɛ meka sɛ nnoɔma a yɛde kata yɛn ho a, wo nso wobɛtumi abobɔ nnoɔma bi te sɛ: 'Hyɛɛte'; tae anaasɛ ɛkyɛ. Wobɛtumi adwene nnoɔma foforɔ bi a yɛde kata yɛn ho?

Wait for the subject to give two words. If the subject succeeds, indicate that the responses were correct and proceed to the test itself. If the subject gives an inappropriate word or reply, correct the response and repeat the instructions. If it becomes clear that the subject still does not understand the instruction, terminate this task and explain why this is so. After you are satisfied that the subject understands the task, and has given two words naming articles of clothing, say:

Woayɛ adeɛ. Mepɛ sɛ wobobɔ din a ɛgyina hɔ ma ekuo foforɔ: "Mmoadoma". Mepɛ sɛ wodwene mmoadoma ahodoɔ a wonim wɔn din nyinaa ho. Dwene mmoa a wɔwɔ wiem, asase so, nsuo mu, kwaeɛ mu, ne mmoa ahodoɔ nyinaa ho. Wowɔ sima baako pɛ a wode bɛbobɔ mmoa a wonim nyinaa din. Woasiesie wo ho? Firi aseɛ.

(The score is the sum of acceptable animals. Any member of the animal kingdom, real or mythical is scored correct, except repetitions and proper nouns. Specifically, each of the following gets credit: a species name and any accompanying breeds within the species; male, female and infant names within the species)

Allow one minute precisely. If the subject stops before the end of the time, encourage them to try to find more words. If they are silent for 15 seconds repeat the basic instruction ('I want you to tell me all the animals you can think of'). No extension on the time limit is made in the event that the instruction has to be repeated.

Mepɛ sɛ wobobɔ mmoa a wonim nyinaa din kyerɛ me

19. (ANIMAL) Number of animals in one minute

20. Mereba abɛbobɔ ɛniɛma mmiɛnsa bi din na mepɛsɛ wobɛbobɔ di makyi.
Kodoɔ
Efie
Nsuo mu nam

Interviewer (score one point for each correct word on first attempt).

20.1{WORDIMM}
First trial score

No words remembered 0
1 Word remembered 1
2 Words remembered 2
3 Words remembered 3

Then go on to repeat the three words, up to a total of **six times** until the subject has remembered them all correctly.

20.2 {TRIALNO}
Record number of trials until repeated successfully

Mo wayɛ adea. Bɔ mmɔden kae nsɛm a m'aka yi. Mebisa wo akyire yi.

21. {TOWN}
Saa kuro yi din de sɛn?

Incorrect 0
Correct 1

22. Ɔhene/Aban krakye panin a wɔwɔ kuroyimu din de sɛn?

Incorrect 0
Correct 1

23. {RIVER}
Nsuo a ɛbɛn ha din de sɛn?

Incorrect 0
Correct 1

24. {MARKET}

Ɛmpɔtam ha dwa wɔ hen?

Incorrect 0
Correct 1

25. {ADDRESS}

Hwan na ɔte bɛn wo wɔ baabi a wote no?

Incorrect 0
Correct 1

26. {WORDDEL}

Wokae nsɛm mmiɛnsa a mekakyerɛ wo a ɛnkyɛreyɛ no?

No words remembered 0
1 Word remembered 1
2 Word remembered 2
3 Word remembered 3

27. (LONGMEM) Long-term memory

Hwaɛn na ɛboaɛ ma Ghana nya faahodie wɔ afe apem, ɔha nkron ne aduonum nson? **(Kwame Nkrumah)**

Incorrect 0
Correct 1

The key to this is to give the participant the date and the event and ask them for the identity of the famous person who was involved. The event should be so well known that practically no non-demented person should get it wrong!

Mepɛsɛ mebisa wo nsɛm a ɛfa ɛmmerɛ ho.

28. {MONTH}

Bosome bɛn mu na yɛwɔ yi?

Incorrect 0
Correct 1

29. (DAY)

Ɛnnɛ yɛ dabɛn?
Incorrect 0
Correct 1

30. (YEAR)

Afe bɛn mu na yɛ wɔ yi?

Incorrect 0
Correct 1

31. {SEASON} #

Ɛbɛrɛ bɛn mu na yɛwɔ yi?

Incorrect 0
Correct 1

(Wet or dry were the appropriate alternatives in Ghana**)**

Merebɛma wo ayɛ nneɛma bi. Nti mepawokyɛw tie no yie efiri sɛ meka a mensi so bio.

(Interviewer – give complete instructions at one time, do not give step by step)

32. {NOD} Bɔ wotiri nko

Incorrect 0
Correct 1

33. {POINT} Fa wo nsa kyerɛ mpoma no so na afei fa kyerɛ pono no so.

Incorrect 0
Correct 1

34. {PAPER}

Meebɛma wo krataa bi. Me dima wo a fa wo nsa bankum gye krataa no. Fa wo nsa mienu buka krataa no mu na fa to wo serɛ so.

Score one point for each component carried out correctly

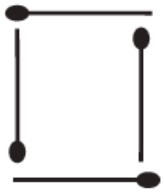
Completely incorrect 0
Uses left hand 1
Folds in two 1
Places on lap 1

(Maximum score = 3)

35. Mɛpɛ sɛ wobɛfa me pɛnsere yi na adeɛ a wadrɔɔ wɔ krataa yi so no wonso wɔbɛdrɔɔ bi wɔ aseɛ hɔ.

See figures below

35.1: {SQUARE} Score for 4-Stick design



Incorrect 0
Correct 1

Score one if the shape of the design is closely imitated to resemble the above 4-Stick Design.

35.2: {PENTAG} Score for 4-Stick Design

Incorrect 0
Correct 1

Score one if the shape of the design is closely imitated to resemble the 4-Stick Design above.

36. Me bɛto ananse sɛm bi akyerɛ wo na mɛma wo aka asɛm no sɛdea me kaa no no sɛdea wokae no.

Three children were alone at home and the house caught on fire. A brave man managed to climb in a back window and carry them to safety. Aside from minor cuts and bruises, all were well.

Na mmɔfra miɛnsa bipɛ ɛwɔ fie na egya tɔɔ mu. Ɔbarima kokoɔdurufoɔ bi faa afikyire ɛpono no mu kɔyii mmɔfra no. Sɛ woyi sɛ wɔhonam twitwiri kakra a wɔnom nyinaa nyaa nkwa.

Now I would like you tell me the story in as much detail as possible.

36. {STORY}

Story recall – total items recalled
Interviewer – score one point for each component correctly recalled

Mmɔfra mmiɛnsa	1
Egya tɔɔ efie no mu	1
Barima kokoɔdurufoɔ bi fro akyere pono no	1
Yɛye mmɔfra no firi egya no mu	1
Wɔhonam twitwiri kakra	1
Obiara nyaa nkwan	1

(Maximum score = 6)

Appendix I: EURO-D Scale Questionnaire (Twi)

10/66 Awirefire Ho Nhwehɛmu Kuo
Nnipa No Ho Nsɛm Nhwehwɛmu
Ɔpɛpon 2015

10/66 Dementia Research Group
Population-Based Study
January 2015

EURO-D SCALE

---

1 (AHYƐNSO DEƐ)

Ɛda a a nkɔmodie yi kɔɔ so: {DATE} <dd/mm/yy>
Enter date as day/month/year, e.g. <05/10/2015>

Nea ɔrebisa nsɛm no ahyɛnso nɔma: {INTERID}
Interviewer ID number

Abusua kuo ahyɛnso nɔma: {HOUSEID}
Household ID number

Obi a ɔka dwumadie yi ho ahyɛnso nɔma: {PARTICID}
Participant ID number

Yɛ pɛ sɛ, yɛ hunu ɔhaw dodoɔ a nkrɔfoɔ wɔ wɔ bosome baako atwa mu yi. Ɛmma no ɛnha wo sɛ yɛrɛ bisa saa nsɛm yi. Ɛyɛ nsɛm a yɛbisa obiara.

All of the following questions refer to the last one month.

MH1. [GMS 21] DEPRESSION – AWERƐHOƆ

Wɔ bosome baako atwa mu yi wo werɛ aho?

Aane 1

Dabi 2

QbyQ: If participant asks for clarification, say 'By sad or depressed, we mean miserable, in low spirits, or blue'

MH2. [GMS 29] PESSIMISM- ƐNSI YIE ATENKA

Ɛdeɛn na wususu hu sɛ ɛbɛba wɔ wo daakye?

ANY hopes mentioned 1

NO hopes mentioned 2

MH3. [GMS 30] WISHING DEATH

Ɛwɔ bosome baako a atwa mu yi, wo nya atenka bi wɔ womu sɛ wo wuu yɛ anaa wokuu wohu anka ɛyɛ?

Any mention of suicidal feelings or wishing to be dead 1

No such feelings mentioned 2

QbyQ: This question asks about a specific wish, or preference to be dead. For participants who express ambivalence about living or dying, **code 2.** ANY wish or preference to be dead would be coded **1,** even if the participant has felt this only occasionally in the last month

EXAMPLES

Code 1 *Any mention of suicidal feelings or wishing to be dead*

"Yes"

"Sometimes, I feel that, but not for long"

"Yes, I want to die now, my life is over"

"I'm looking forward to my death so I can see my husband again'

Code 2 *No such feelings mentioned*

"I don't really care if I die now, I feel I'm at the end of my life"

"I don't mind. I take each day as it comes"

MH4. [GMS104] GUILT – BƆNE HO AHUNAHUNA

Ɛyɛ a wo nunu woho wɔ biribi ho anaa sɛ wote nka sɛ woso nni mfasoɔ?

Obvious excessive guilt or self blame 1

No such feelings 2

Mentions guilt or self-blame, but it is unclear if these constitute obvious or excessive guilt or self blame 3

IF 1 OR 2 THEN GO TO MH5
IF 3 THEN ASK–

MH4.2 Nti deɛn na ɛma wonu wohu anaa wo di ɛfɔ wɔ biribi ho?

Example(s) given constitute obvious excessive guilt or self blame 1
Example (s) do not constitute obvious excessive guilt or self blame, or it remains unclear if these constitute obvious or excessive guilt or self blame 2

QbyQ *–Only* ***Code 1*** *for an exaggerated feeling of guilt that is clearly out of proportion to the circumstances. The fault will often have been very minor, if it there was one at all. Justifiable or appropriate guilt should be* ***Coded 2.***

EXAMPLES

Obvious excessive guilt or blame (**Code 1**)

Unusually, very severely depressed people may have lost touch with reality e.g. "The September 11th attack on the World Trade centre was my fault. I am to blame"

More commonly, depressed older people feel responsible in an exaggerated way for bringing harm or hurt to those around them

"I am a burden on my children. I am useless and just hold them back"

Trivial, justifiable or appropriate guilt (**Code 2**)

"I left my wife and haven't seen much of my children. I blame myself for this"

"I have not been as kind or considerate to people as I should"

MH5. [GMS54] SLEEP – NDA/ADA

Nansa yi wo nna mu ho ayɛ den?

Trouble with sleep or recent change in sleep pattern	1
No trouble sleeping	2

QbyQ – Any trouble sleeping is coded here. Specifically, sleep problems attributed to need to get up to pass water, bodily pain or discomfort, or noisy environment should still be **coded 1**

MH6. [GMS113] INTEREST – MFƐMTOM

MH6.1 Wɔ bosome a atwa mu yi sɛn na wani gye ɛneɛma bi ho fa?

Less interest than is usual mentioned	1
No change in levels of interest mentioned	2
Non-specific or uncodeable response	3

IF 1 OR 2 THEN GO TO MH7
IF 3 THEN ASK-

MH6.2 Nti, ɛyɛ a wo yɛ ma w'ani gyeɛ no gyina so?

Dabi	1
Aane	2

MH7. [GMS105] IRRITABILITY–ABUFUO HYƐ

Wo bo taa fu nansa yi?

Aane	1
Dabi	2

MH8. [GMS51] APPETITE – AKƆNƆ

MH8.1 Wanum te ma wotumi didi anaa sɛ wokɔn nnɔ ɛduane?

Diminution in the desire for food	1
No diminution in the desire for food	2
Non-specific or uncodeable response	3

QbyQ – It is APPETITE (desire for food) that is being asked about here. Someone who is eating less because of a diet, but does not have any 'diminution in the desire for food' should be **coded 1**

IF 1 OR 2 THEN GO TO MH9 IF 3 THEN ASK-

MH8.2 Nti, wodidi kyɛn kanee anaa ɛso ate?

ɛso ate / Less	1
Kyɛn kanee no / More	2
Te sɛ kanee no / Neither more nor less	3

QbyQ – Again, someone who volunteers that they are eating less than usual, but because of a deliberate diet should be **Coded 3**

MH9. [GMS72] FATIGUE - ƆBRƐ

Wɔ bosome a atwamu wo ahoɔden kɔ fam a ɛmma wontumi nyɛ biribi a anka wopɛsɛ woyɛ?

Aane	1
Dabi	2

MH10. [GMS117/118] CONCENTRATION - MMOANO

MH10.1 [GMS117]

Sɛn na wotumi de w'adwene si biribi so te sɛ worehwɛ TV/Cini na wotumi hwɛ kosi awieɛ a wote aseɛ?

Difficulty in concentrating on entertainment mentioned	1
No such difficulty mentioned	2

QbyQ – Participants who are blind should just be asked about concentrating on a radio programme. Other should be asked about 'a television programme, a film or a radio programme'

MH10.2 [GMS 118] Wotumi kenkan nwoma / biribi ma wode wadwene si so kan kosi awieɛ?

Difficulty in concentrating on reading mentioned	1

No such difficulty mentioned 2

QbyQ – For those who cannot read because of blindness or illiteracy, a missing value code will be entered

MH11. [GMS114] ENJOYMENT – ANIGYEƐ

Ɛdeɛn na woyɛɛ nansa yi a w'ani gyee ho?

Fails to mention any enjoyable activity 1

Mentions ANY enjoyment from activity 2

MH12. [GMS22] TEARFULNESS - ASUNISUO

Bosome a atwa mu wosu da?

Aane 1

Dabi 2

QbyQ – Any episode of crying would be **coded 1** 'yes', no matter what the cause. For example, crying over a scene in a film. Do check (if it is unclear from their answer) that the participant is describing crying IN THE LAST MONTH. If necessary, you should repeat the question, stressing this element.

Appendix J: Socio-demographic & Risk Factor Questionnaire I (Twi)

10/66 Awirefire Ho Nhwehɛmu Kuo Nnipa no Ho Nsɛm Nhwehwɛmu

Ɔpɛpon 2015

10/66 Dementia Research Group Population-Based Study

January 2015

Socio-Demographic and Risk Factor Questionnaire

PARTICIPANT VERSION

THE INTERVIEWER SHOULD ATTEMPT TO COMPLETE THE PARTICIPANT VERSION OF THIS INTERVIEW FOR ALL PARTICIPANTS. THE ACCOMPANYING INFORMANT VERSION SHOULD ONLY BE USED IF

A) IT IS IMPOSSIBLE TO GET THE INFORMATION FROM THE PARTICIPANT AND THE PARTICIPANT VERSION HAS NOT BEEN COMPLETED, OR

B) THE INTERVIEW IS WORRIED ABOUT THE RELIABILITY OF THE INFORMATION FROM THE PARTICIPANT AND WANTS TO GET INFORMATION FROM THE INFORMANT ALSO

---

1. IDENTIFIERS

Ɛdaa nkɔmodie yi kɔɔ so: {DATE} ‹dd/mm/yy›

Enter date as day/month/year, e.g. <05/10/2003>

Ɔrebisa nsɛm no ahyɛnso nɔma: {INTERNID}

Interviewer ID number:

Abusua kuo ahyɛnso nɔma: {HOUSEID}

Household ID number:

Obi a ɔka dwumadie yi ho ahyɛnso nɔma: {PARTICID}

Participant ID number:

2.1 {PINTER}

This sociodemographic/risk factor interview was conducted with:

Participant only 0

Participant and informant 1

---

3. EARLY LIFE

3.1 {PLIVED} **Ɛmerɛ tenten/Mfie dodoɔ sɛn na watena ha?**

3.2 {PBORN} **Yɛwoo wowɔ hee?**

Kuro kɛseɛ mu	0
Kuro ketewa mu	1
Akuraa	2

3.3 {PMIDLIFE} **Wo dii mfie aduonu kɔpim aduosia ntamu no ɛhee na w'atena kɛse?**

Kuro kɛseɛ mu	0
Kuro ketewa mu	1
Akuraa	2

3.4 {PLATLIFE} **Wo dii mfie aduosia no, ɛhee na wo tenaa kɛse?**

Kuro kɛseɛ mu	0
Kuro ketewa mu	1
Akuraa	2

3.5 {PEDUC} **Wo kɔɔ sukuu kɔduru sɛn?**

Mankɔ bi koraa	1
Mekɔɔ kakra nanso manwie primire sukuu	2
Mewiee Primire Sukuu	3
Mewiee Sɛkandiri Sukuu/Mewiee College	4
Mewiee College/Ni Akyire	5

3.6 {PREAD} **Wobɛtumi akenkan dawubɔ krataa?**

Dabi	0
Aane	1

3.7 {PWRITE} **Na wotumi twerɛ krataa sɛ ɛho behia saa a?**

Dabi	0
Aane	1

---

4. CURRENT CIRCUMSTANCES

4.1 {PHEADHSE} **Wo ne abusua kuo no ti?**

Dabi	0
Aane	1

IF YES CONTINUE TO 4.3

4.2 {PREL} **Hwan ne abusua kuo no ti/Hwan na ɔda abusua kuo no ano?**

Me Hokani	1
Me Ba Barima/Baa	2
Ase Barima/Baa	3
Nua Barima/Baa	4
Busuani	5
Adamfoɔ	6

4.3 {PMARRY} **Seisei ara yi waware?**

Menware da	1
Maware/me ne obi te hɔ	2
Meyɛ kuna ni/foɔ	3
Magyae awadeɛ	4

4.4 {PRELIG} Woka ɔsom bi ho / Wowɔ som bi mu?

Agnostic/Atheist	0
Roman Catholic	1
Anglican/Protestant	2
Other Christian	3
Jewish	4
Muslim	5
Buddhist	6
Hindu	7
Other (inc. Traditional / Spiritual Religions)	8

4.5 {PGOCHCH} **Wokɔ / Wo tae kɔ ɛsom nhyiamu?**

Dabi	0
Aane dabiara	1
Aane dakoro dakoro	2

4.6 {PCLUBS} **Wokɔ mpɔtam ha / ekuo bi nhyiamu**?

Dabi	0
Aane dabiara	1
Aane dakoro dakoro	2

---

5. SOCIAL NETWORK

5.1 {PRELDIST} **Wo ne wobusuani a ɔte bɛn wopaa ntam kwan bɛyɛ sɛn?**

Bɛyɛ kwanisin baako / Ɛfie koro mu	1
Kwansin baako kɔsi num	2
Kwansin nsia kɔsi dunum	3
Kwansin dunsia kɔsi aduonum	4
Ɛboro kwansin aduonum	5

5.2 {PSIBDIST} **Bɛyɛ kwansini sɛn na wo nua a ɔte bɛn wo no wɔ?**

Menni nua	0
Bɛyɛ kwanisin baako / Ɛfie koro mu	1
Kwansin baako kɔsi num	2
Kwansin nsia kɔsi dunum	3
Kwansin dunsia kɔsi aduonum	4
Ɛboro kwansin aduonum	5

5.3 {PCH} **Wowɔ mma?**

Dabi	0
Aane	1

IF NONE SKIP TO 5.6

5.4 {PCHDIST} **Wo ba a ɔte bɛn wo paa no te bɛyɛ kwansini sɛn firi fie ha?**

Menni ba	0
Bɛyɛ kwanisin baako / Ɛfie koro mu	1
Kwansin baako kɔsi num	2
Kwansin nsia kɔsi dunum	3
Kwansin dunsia kɔsi aduonum	4
Ɛboro kwansin aduonum	5

5.5 {PRELFRQ} **Ɛmperɛ dodoɔ sɛn na wohunu wo mma anaa abusuafoɔ no bi ne wɔn kasa?**

Mennhu bi	0
Dabiara	1
Mperɛ mienu kɔsi miɛnsa naawɔtwe mu	2
Anyɛ koraa no; naawɔtwe biara	3
Anyɛ koraa no; bosome biara	4
Yɛ nntae nkasa	5

5.6 {PFRD} **Wo wɔ nnamfoɔ wɔ mpɔtam ha?**

Dabi	0
Aane	1

IF NONE SKIP TO 5.10

5.7 {PFRDFRQ} **Ɛmperɛ dodoɔ sɛn na wone w'adamfo bi di nkɔmɔ anaa wo ne no yɛ biribi?**

Menni adamfoɔ / ɛnsii da	0
Dabiara	1
Bɛyɛ mperɛ mienu kosi miɛnsa nawɔtwe biara	2
Anyɛ koraa no nawɔtwe biara	3
Anyɛ koraa no bosome biara	4
Ɛntae nnsi	5

5.8 {PFRDNUM} **Wo namfo a ɛbɛn wo bɛn na wɔtaa ne wɔn hyia anyɛ koraa no bosome biara** (**at least once a month**)? **Wɔn din a edi kan ne sɛn? (e.g. 'Peter"Mrs. B')?**

(Code **number** of friends positively identified)

5.9 {PFRDSAT} **Ɛmoa a wonya firi wo namfo hɔ no sɔ w'ani anaa nnsɔ w'ani?**

Ɛnnsɔ ani	0
Ɛsɔ ani	1

5.10 {PNEIFRQ} **Ɛmperɛ dodoɔ sɛn na wo ne wɔn a wɔte wo borɔno no so di nkɔmɔ anaa yɛ biribi?**

Ɛbi nnihɔ	0
Dabiara	1
Bɛyɛ mperɛ mienu kosi miɛnsa nawɔtwe biara	2
Anyɛ koraa no nawɔtwe biara	3
Anyɛ koraa no bosome biara	4
Ɛntae nnsi?	5

5.11 {PNEINUM} **W'afipamfoɔ papa paa dodoɔ sɛn na wone wɔn taa hyia di nkɔmɔ borono no so (anye koraa no ɛperɛ bako bosome mu)? Wɔn din a edi kan ne sɛn (e.g John, Mr. Foffie etc.)?**

(Code **number** of neighbours identified)

---

6. SOCIO-ECONOMIC STATUS

6.1 {PJOB} **Wo wɔ / Wo yɛ adwuma bi a...**

Woyɛ gye akatua berebiara	1
Wonyɛ no dabiara	2
Nni adwuma	3
Adesuani	4
Ɔyere / Ekunu (Full time)	5
Mewɔ ahomegyeɛ mu	6

6.2 {PJOBCAT} **Adwuma papa paa bɛn na wayɛ pɛn? Adwuma bɛn na woyɛɛ wɔ mu?**

(CODE LOWEST APPLICABLE NUMBER)

Adwuman panin - Manager/Administrator	1
Nimdefoɔ wɔ ebia apɔmuden, adekyerɛ, mmara anaa sikasɛm mu- Professional (e.g. health, teaching, legal, financial)	2
Nimdefoɔ foforɔ wɔ Nfidie Nsiesie, Nɛɛse Adwuma anaa Adwinnie mu -Associate Professional (e.g. Technical, Nursing, Artistic)	3
Ɔfese Odwumayɛni / Ɔtwerɛtwerɛfo-Clerical worker - Secretary	4
Sotɔɔ Hwɛfoɔ - Shopkeeper	5
Nsaanodwumayɛni wɔ Adansie anaa Anyinam Ahɔden Dwumadie mu- Skilled labourer (e.g. building, electrical etc.)	6
Nsaanodwuma mu Boafoɔ - Semi-skilled Labourer (e.g. Helper of Skilled Labourer)	7
Ɔnni Nsaanodwuma - Unskilled labourer	8
Kuadwuma mu Odwumayɛni - Agriculatural Worker	9
Missing Value	99

6.3 {PCJOBCAT} **Adwuma papa paa bɛn na wohokani yɛɛ da? Adwuma bɛn na wɔyɛɛyɛ wɔ saa adwuma no mu?**

(CODE LOWEST APPLICABLE NUMBER)

Adwuman panin - Manager/Administrator	1
Nimdefoɔ wɔ ebia apɔmuden, adekyerɛ, mmara anaa sikasɛm mu -Professional (e.g. health, teaching, legal, financial)	2
Nimdefoɔ foforɔ wɔ Nfidie Nsiesie, Nɛɛse Adwuma anaa Adwinnie mu- Associate Professional (e.g. Technical, Nursing, Artistic)	3
Ɔfese Odwumayɛni / Ɔtwerɛtwerɛfo - Clerical worker / Secretary	4
Sotɔɔ Hwɛfoɔ - Shopkeeper	5
Nsaanodwumayɛni wɔ Adansie anaa Anyinam Ahɔden Dwumadie mu - Skilled labourer (e.g. building, electrical etc.)	6
Nsaanodwuma mu Boafoɔ - Semi-skilled Labourer (e.g. helper of skilled Labourer)	7
Ɔnni Nsaanodwuma - Unskilled labourer	8
Kuadwuma mu Odwumayɛni - Agriculatural Worker	9
Missing Value	99

6.4 {PINCOME} **Wo gye sika bi sɛ ɛyɛ pension anaa akatua foforɔ bi?**

Dabi	0
Aane	1

IF NO, SKIP TO SECTION 7. IF YES...

Wonya sika, bɔtom sika, anaa mfasoɔ bi?

Benefit type

Aban Pɛnhyɛn – Government Pension	1
Ankorankoreɛ Pɛnhyɛn – Occupational Pension	2
Ɛdɛmdie Pɛnhyɛn anaa Mfasoɔ bi – Disability Pension/Benefit	3
Sika a ɛfiri abusuafoɔ hɔ – Money from family	4
Sika a ɛfiri ɛdan a wɔde ahane mu – Income from rented land/property	5
Sika a ɛfiri adwuma akatua mu – Income from paid work	6
Afoforɔ bi – Other	7
Sika foforɔ biara nni hɔɔ – No further benefit	9

Type of Benefit	**Monthly Income**
6.5 {BENTYPE1}	**6.6** {BEN1}
6.7 {BENTYPE2}	**6.8** {BEN2}
6.9 {BENTYPE3}	**6.10** {BEN3}
6.11 {BENTYPE4}	**6.12** {BEN4} (**MV = 9999**)

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7. HEALTH

7.1 {PTOLDBP} **Dɔkta aka akyerɛwo sɛ wowɔ mogya morosoɔ pɛn?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.5

7.2 {PBPYEAR} **Berɛ bɛn na ediikan a yɛka saa kyerɛɛ wo?**

Mfie num a atwam	1
Mfie num kosi mfie du atwam	2
Mfie du anaa aboro saa atwam	3

7.3 {PBPTREAT} **Yɛde wo too aduro bi so?**

Dabi	0
Aane	1

7.4 {PBPCON} **Wo daso nom aduro no?**

Dabi	0
Aane	1

7.5 {PTOLDHRT} **Dɔkta aka akyerɛ wo da sɛ wowɔ akoma yadeɛ?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.8

7.6 {PHRTYEAR} **Berɛ bɛn na edi kan?**

Mfie num a atwa mu	1
Mfie num kosi mfie du atwa mu	2
Mfie du anaa aboro atwa mu	3

7.7 {PHRTWHAT} **Na dɔkta no se ɛyɛ deɛn?**

Heart Attack	1
Angina (Ɛyɛ a wo bo twetwe wo, yɛ wo ya paa / Ɛyea wo bo so yɛ wo tesɛ deɛ y'aso mu twe)	2
Heart Failure	3
Valve disease	4
Other – Bibi wɔhɔ a yɛn mmɔ su	5

7.8 {PCVA} **Woanya stroke da a ehiaa sɛ dɔkta bɛhwɛ wo? Ɛkɔsii sɛn**?

Dabi	0
Aane	1

IF NO, SKIP TO 7.10

7.9 {PCVADIAG} **Hwan na ɔhwehwunu sɛ w'anya saa stroke no bi?**

Ɛnyɛ obiara	0
Dɔkta	1
Dɔkta a w'akwa dare wɔ stroke yareɛ mu	2

7.10 {PTIA} **Aba pɛn, sɛ w'anya putupru apɔmu merɛ a w'anntumi nkasa, anaa sɛ, w'annhunu adeɛ papa, nanso aankyɛ a ɛdii bɛyɛ da baako pɛ?**

Dabi	0
Aane	1

7.11 {PLOC} **Aba pɛn sɛ woanya pira keseɛ bi wɔ wotiri ho a ɛmaa wo tɔre mum?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.15

7.12 {PLOCHRS} **7.13** {LOCMINS}

ɛmerɛ dodoɔ sɛn na wo tɔre mum no?

7.14 {PLOCAGE} **Saa bere no na w'adi mfie sɛn?**

7.15 {PTOLDDM} **Dɔkta aka akyerɛwo sɛ wo wɔ asikyire yadeɛ pɛn?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.17

7.16 {PDMTRT} **ɛnti no wo hia aduane soronko bi, wonom nnuro anaa wowɔ paneɛ?**

Aduane nkoa	1
Me nom aduro	2
Mebɔ paneɛ	3
Menyɛ aduro biara	4

7.17 {PCOAD} **Sɛ eduru awɔberɛ a wo tae bɔ wa yi ahorɔ anɔpa**?

Dabi	0
Aane	1

IF NO, SKIP TO 7.19

7.18 {PCOAD1} **Bosome dodoɔ sɛn na saa adeɛ yi ba wɔ afe no mu?**

ɛnnuru bosome miɛnsa	1
Bosome miɛnsa ne akyire	2

7.19 {PMAL} **Woanya atiridie yadeɛ da? Ɛberɛ bɛn?**

Me nnyaa bi da	0
Mfie num a atwam	1
Ɛboro mfie num nie	2

7.20 {PTB} **Wabɔ nsamanwa da? Ɛberɛ bɛn a?**

Me nnyaa bi da	0
Mfie num a atwam	1
Ɛboro mfie num nie	2

7.21 {PCYST} **Woanya Cysticercosis da? Ɛberɛ ben?**

Me nnyaa bi da	0
Mfie num a atwam	1
Ɛboro mfie num nie	2

7.22 {PPASTHX} **Ɛberɛ bi aba wɔ wasetenamu a wo werɛ hooyɛ, anaa wo yɛɛ din a na w'ani ngye wɔ ɛneɛma bi te sɛ adwuma yɛ, agorɔ die a ɛtoa mu bɛyɛɛ nawɔtwe mienu?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.26

7.23 {PONSDEP} **Saa bere a edikan no na w'adi mfei sɛn?**

7.24 {PDOCRX} **W'abusua dɔkta anaa dɔkta bi a ɔhwɛ adwenemu yadeɛ bɛhwɛɛwo?**

Dabi	0
Aane	1

7.25 {PADMIT} **Yɛ gyee wotoo ayaresabea a wɔhwɛ adwenemu yadeɛ?**

Dabi	0
Aane	1

7.26 {PFHDEM} **W'abusuafoɔ paa te sɛ w'awofoɔ anaa wo nuanom bi anya yadeɛ bi a ɔntumi nkae biribiara a ɛmaa no baa sɛ ɔntumi nhwɛ neho mpo?**

Dabi	0
Aane	1

IF NO SKIP TO SECTION 8

Busuani bɛn na anyaa saa haw yi?

7.26.1 Wo Papa? {PFATHER}

Onyaa bi 0
Abakɔsɛm kyerɛ sɛ w'annya bi 1

Ɛhyɛɛ aseɛ na wadi mfie sɛn? {PFATHAGE}

7.26.2 Wo Maame? {PMOTHER}

Onyaa bi 0
Abakɔsɛm kyerɛ sɛ w'annya bi 1

Ɛhyɛɛ aseɛ na wadi mfie sɛn? {PMOTHAGE}

7.26.3 Wo nua barima / baa a odi kan? {PSIB1}

Onyaa bi 0
Abakɔsɛm kyerɛ sɛ w'annya bi 1

Ɛhyɛɛ aseɛ na wadi mfie sɛn? {PSIBAG1}

IF NO (0) SKIP TO SECTION 8

7.26.4 Wo nua barima / baa ɔtɔsu mienu? {PSIB2}

Onyaa bi 0
Abakɔsɛm kyerɛ sɛ w'annya bi 1

Ɛhyɛɛ aseɛ na wadi mfie sɛn? {PSIBAG2}

IF NO (0) SKIP TO SECTION 8

7.26.5 Wo nua barima / baa ɔtɔsu miensa? {PSIB3}

Onyaa bi 0
Abakɔsɛm kyerɛ sɛ w'annya bi 1

Ɛhyɛɛ aseɛ na wadi mfie sɛn? {PSIBAG3}

IF NO (0) SKIP TO SECTION 8

7.26.6 Wo nua barima / baa a ɔtɔsu nnan? {PSIB4}

Onyaa bi 0
Abakɔsɛm kyerɛ sɛ w'annya bi 1

Ɛhyɛɛ aseɛ na wadi mfie sɛn? {PSIBAG4}

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8. IMPAIRMENT

8.1 Merebɛbobɔ nyarewa bi din na baako biara no mepɛsɛ wo bɛka akyerɛ me sɛ ebia wo wɔ saa yarewa no bi seisei anaa saa berɛ yi?

8.1.1 Ahotutuo? {PARTH}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.2.1 Aniyadeɛ? {PEYE}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.3.1 Asosie? {PEAR}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.4.1 Ɛwa? {PCOUGH)

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.5.1 Korɔtoa/Ntehyeewa? {PRESP}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.6.1 Mogya morosoɔ? {PBP}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.7.1 Akoma yadeɛ? {PHEAR}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.8.1 Yafun mu anaa Nsonomu yadeɛ? {PGUT}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.9.1 W'atu atiwee? {PFAINT}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.10.1 Ne fa adwoduo/Nndwedweyɛ? {PLIMB}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

8.11.1 Honam ani yadeɛ; akuro a ɛnkɔ da, anaa hyehyeɛ a ano ɛden? {PSKIN}

IF YES

Kwan bɛn so na ɛha wo; ɛnnha me koraa, ɛha me kakra, ɛhame paa?

Me nni saa yadeɛ no bi	0
Mewɔ bi nanso ɛnnha me	1
Mewɔ bi nanso ɛnnha me kɛse	2
Mewɔ bi na ɛha me paa	3

---

9. YAW PAIN

9.1 {PPAIN1}

Bɛyɛ bosome ni mperɛ dodoɔ sɛn na yadeɛ bi aha wo a ɛyɛ ya paa?

Ebi nsii da	1
Bɛyɛ mprenu/mprɛnsa wɔ bosome a atwa mu no	2
Prɛko nawɔtwe biara mu	3
Naanu/mprɛnsa nnawɔtwe	4
Dabiara	5

IF NEVER (1) SKIP TO 10.1

9.2 {PPAIN2}

Wɔ bosome a ɛtwan mu no, na ɛhaw anaa yeyaa no ano den te sɛn?

Yɛya ketewaa bi	1
Yɛya a ano yɛden kakra	2
Yɛya a ano yɛden paa	3
Yɛya a ano yɛden papaa pa	4
Yɛya a wontumi ngyina ano	5

9.3 {PPAIN3}

Sɛ yɛya no ba paa a, kwan bɛn so na ɛsi neɛma woyɛ ho kwan?

Ɛnsi bibiara ho kwan koraa	1
Ɛnsi kwan kɛse	2
Ɛsi kwan kakra	3
Ɛsi kwan kɛse paa	4

---

10. DISABILITY

10.1{PDASALL1}

Bɛyɛ sɛ bosome ni sɛn na wohunu wapɔmuden?

Ɛyɛ paa	0
Ɛyɛ	1
Ɛyɛ kakra	2
Ɛnnyɛ	3
Ɛnnyɛ koraa	4

Nsɛm misa a edidisoɔ yi fa ɔhaw a ɛfa apɔmuden ho te sɛ widiɛmu yadeɛ, ɛpira adwendwen, nsanom ne enuro nom ho:

Twa w'ani hwɛ wakyi bɛyɛ sɛ bosome ni na kyerɛ ɛhaw a wo faa mu sɛ woreyɛ saa neɛma yi a.

For each question, please circle only one response

BOSOME NI:

10.2 {PDAS1} **Sɛ wogyina hɔ bɛyɛ sima aduasa a woberɛ / wohaw te sɛn?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.3 {PDAS2} **Sɛ woreyɛ wofie neɛma?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.4 {PDAS3} **Woresua adefoforɔ bia? Te sɛɛ yɛ kyerɛɛ wo afa kwan foforɔ bi su a wo nfaa su da?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.5 {PDAS4} **Sɛ wobɛhyia ayɛ kwasafo adwuma / wobɛka afahyɛ bi hu / akuo bi hu / adeyɛ bi a obiara tumi yɛ?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.6 {PDAS5} **Wohwee a w'apɔmu den a sɛnna ateete wo afa, anaa sɛn na woyadeɛ no ahaw wo afa?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.7 {PDAS6} **Sɛ wode w'adwene si biribi so ayɛ atoaso bɛyɛ sima du a sɛn na ɛhaw fa?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.8 {PDAS7} **Wo nante akɔ bɛyɛ kwansin baako ɛ?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.9 {PDAS8} **Wo dware wo ho so ɛ?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.10 {PDAS9} **Wo siesie wo ho ɛ?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.11 {PDAS10} **Sɛ wone nnipa bi a wo nnim wɔnom ɛhyia na mo di nkutaho a ɛyɛ a wo wɔ haw bi?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.12 {PDAS11} **Wowɔ haw sɛ wotoa wonamfofa so?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.13 {PDAS12} **Wowɔ haw sɛ wotoa wo daadaa dwumadie ne neɛma a woyɛ su?**

Menni haw	0
Ɛhaw ketewaa bi	1
Ɛhaw kese	2
Ɛhaw kesɛɛ paa	3
Ɛhaw kesɛɛ a ɛboro so a mentumi	4

10.14 {PDASLL2} **Nsusansoɔ a saa ɔhaw yi nyaa wɔ w'abrabɔ so?**

Ɛnnya nsusansoɔ biara	0
Ɛnya nsusansoɔ ketewa bi	1
Ɛnya nsusansoɔ kese	2
Ɛnya nsusansoɔ kesɛɛ paa	3
Ɛnya nsusansoɔ kesɛɛ ɛboro so a mentumi	4

10.15 {PDASALL3} **Bɛyɛ bosome bako ntam no, mprɛn dodoɔ sɛn na saa ɔhaw yi kɔɔ so?**

MV=99

10.16 {PDASALL4} **Bɛyɛ bosome bako ntam no, ɛnna dodoɔ sɛn na w'anntumi annyɛ w'adwuma koraa ɛsan w'pɔmuden no nsɛm nti?**

MV=99

10.17 {PDASALL5} **Ɛbɛyɛ bosome bako ntam no, sɛ woyi ɛnna a na woyare a woantumi anyɛ hwee no firi mu a, wotee dwumadie a wotae yɛ no so ɛnam yadeɛ bi nti?**

MV=99

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11 REPRODUCTIVE HEALTH

The following four questions are for women only – Saa nsɛm miɛsa yi kɔ ma mmaa nkoa

11.0{PSEXRE} Enter the participant's gender here

Ɔbaa	1
Ɔbarima	2

IF PARTICIPANT IS (2) SKIP TO SECTION 12

11.1 {PMENARC} **Na w'adi mfie sɛn na wobuu wonsa?**

11.2 {PCHINO} **Wo woo ɛmma sɛn?**

11.3 {PCHIAGE} **Wo woo w'abakan na w'adi mfie sɛn?**

11.4 {PMENPAUS} **Wo twaa bra na w'adi mfie sɛn?**

---

12. BEHAVIOUR AND LIFESTYLES

12.1 SMOKING

12.1 {PSMOKE} **Ɛberɛ bi abɛsen a, na wonom sigrɛte/taa/abua/asera anaa wotwi bonto?**

Dabi	0
Aane	1

IF NO, SKIP TO 12.2

12.1.2 {PSMOKE2} **Ɛmu nea ɛwɔ he na na wo taa nom/twi?**

Sigrɛte	1
Taa	2
Abua	3
Bonto	4
Asera	5

12.1.3 {PSTART} **Wo hyɛɛ aseɛ nom sigrɛte/taa/abua/asera/wotwi bonto no na w'adi mfie sɛn?**

12.1.4 {PSMKNOW} **Wo daso nom sigrɛte/taa/abua/asera/wotwi bonto sɛ deɛ na wonom no kane no?**

Dabi	0
Aane	1

IF YES, SKIP TO 12.1.6

12.1.5 {PSTOP} **Wogyae sigrɛte/taa/abua/asera/bonto nom/twi no na w'adi mfie sɛn?**

12.1.6 {PCIGDOSE} **Sigrɛte/taa/abua/asera/bonto dodoɔ sɛn na na wo nom/twi dakoro biara?**

(MV=99)

12.2 ALCOHOL

12.2.1 {PALCPAST}

Ansa na wobɛdi mfie aduosia num no na nsa dodoɔ paa sɛn na wotumi nom nnawɔtwe biara mu?

(Record maximum regular consumption in units of alcohol per week)

1 Unit = Tɔmɛ Baako, Nsa denden Ketewaa Bi, Wine Tɔmɛ Baako
32 Units = Nsa Denden Akɔtoa,
Me Nim/Mennkae
999 Don't know

12.2.2 {PALCNOW}

Na woboroo mfie aduosia num yi nsoɛ? Nsa dodoɔ sɛn na wotumi nom no nawɔtwe biara mu?

(Record total consumption in units of alcohol)

IF NEVER A DRINKER SKIP TO 12.3

12.2.3 {PHEAVY}

Ɛberɛ bi anaa mfie bi atwa mu a anka wobɛka sɛ na wonom nsa kɛse paa?

Dabi	0
Aane	1

12.2.4 {PALCTRT}

Dɔkta pɛɛ aduro bi ma wo pɛn sɛdea ɛbɛma wo gyae nsanom?

Dabi	0
Aane	1

12.3. DIET

12.3.1 {PMEATFRQ} Mperɛ dodoɔ sɛn na wowe mogya nam?

Mennwe mogya nam	0
Dakoro dakoro / Ɛtɔ dabi a me we	1
Metae we	2
Dabiara me we	3

12.3.2 {PFISHFRQ} Mperɛ dodoɔ sɛn na wowe nsuo mu nam?

Mennwe nsuo mu nam	0
Dakoro dakoro / Ɛtɔ dabi a me we	1
Metae we	2
Dabiara me we	3

12.3.3 {PVEGS}

Ɛbɛyɛ nansa ntam ni no, mperɛ dodoɔ sɛn na w'adi nduaba ne nhabanma? (One fruit or one portion of salad or vegetables counts as a serving)MV=99

12.3.4 {PHUNGER}

Ɛkɔm tumi de wo a ɛnam sɛ aduane nii hɔ nti? Mperɛ dodoɔ sɛn na aba no saa?

Ɛnsii da	0
Ɛtɔ dabi ɛkɔm de me	1
Ɛkɔm ntaa nne me	2
Ɛkɔm di me dabiara	3

12.4 EXERCISE

12.4.1 {PACTIVE}

Sɛ wohwɛ adwuma ne adagyeɛ a wonya a wobɛka sɛ wo?

Wɔ ahoɔden paa	1
Wɔ ahoɔden kakra	2
Nni ahoɔden papa	3
Nni ahoɔden koraa	4

12.4.2 {PWALKANY}

Wo anante atoaso bɛyɛ kwansin anaa sima du kɔsi dunum bosome yi mu?

Dabi	0
Aane	1

12.4.3 {PWALKOFT}

Bosome a etwaa mu yi mperɛ dodoɔ sɛn na wo nantee bɛyɛ kwansin fa anaa ɛboro saa? Sima du kɔpim dunum ntam?

12.4.4 {PPASTEX} **Wo tae tenetene wapɔmu?**

Meyɛ sene nea na meyɛ mfie du a atwamu no	3
Meyɛ tesɛ nea na meyɛ mfie du a atwamu no	2
Me nyɛɛn nnuru nea na meyɛ mfie du a atwamu no	1

---

13. USE OF SERVICES

A. ABAN AYARESABEA NKUMAA ADWUMAYEFUƆ
GOVERNMENT PRIMARY HEALTH CARE PROVIDERS

Ɛbɛyɛ bosome miɛnsa ni w'akɔ aban ayaresabea akɔhu dɔkta anaa ayaresabea adwumayɛfoɔ no bi?

13.1 PRIMARY CARE AYARESABEA NKUMAA

13.1.1 {PPC}

Wakɔ ayaresabea nkumaa yi bi mu bɛyɛ abosome miɛnsa ntam ni?

Dabi	0
Aane	1

IF NO SKIP TO 13.2

13.1.2 {PPCCARE} **Adamfoɔ anaa busuani bi dii wakyi kɔɛ?**

Dabi	0
Aane	1

Sɛ wokɔ baako biara a…

13.1.3 {PPCTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde duru hɔ? (Sima Sɛn)**
MV=9999

13.1.4 {PPCTRCST} **Ɛka sɛn na wobɔ ansa na wa duru hɔ?**

MV=9999

13.1.5 {PPCMINS} **Sɛ wohunu dɔkta noa, ɛmerɛ dodoɔ sɛn na wodi wɔ ne nkyɛn? (Sima Sɛn)**

MV=9999

13.1.6 {PPCCOST} **Ɛka dodoɔ sɛn na wobɔ na wotua ma hwɛ a dɔkta hwɛɛ wo no?**

MV=9999

13.1.7 {PPCVIS} **Bosome miɛnsa ntam yi no, mperɛ dodoɔ sɛn na w'akɔ hunu dɔkta?**

MV=99

13.2 GOVERNMENT HOSPITAL DOCTOR - **ABAN AYARESABEA KESE DƆKTA**

13.2.1 {PHOSP}

Bosome miɛnsa a atwa mu yi wakɔhunu dɔkta bi wɔ aban yaresabea kɛseɛ mu?

Dabi	0
Aane	1

IF NO SKIP TO 13.3

13.2.2 {PHPCARE} **Adamfoɔ anaa busuani bi dii wakyi kɔɛ?**

Dabi	0
Aane	1

Sɛ wokɔ baako biara a…

13.2.3 {PHPTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde duru hɔ? (Sima Sɛn)**

MV=9999

13.2.4 {PHPTRCST} **Ɛka sɛn na wobɔ ansa na wa duru hɔ?**

MV=9999

13.2.5 {PHPMINS} **Sɛ wohunu dɔkta noa, ɛmerɛ dodoɔ sɛn na wodi wɔ ne nkyɛn? (Sima Sɛn)**

MV=999

13.2.6 {PHPCOST} **Ɛka dodoɔ sɛn na wobɔ na wotua ma hwɛ a dɔkta hwɛɛ wo no?**

MV=99999

13.2.7 {PHPVIS} **Bosome miɛnsa ntam yi no, mperɛ dodoɔ sɛn na w'akɔ hunu dɔkta?**

MV=99

13.3 **ABAN AYARESAEA ADWUMAYEFUƆ FOFORO BI** OTHER GOVERNMENT HEALTH WORKER (E.G. PHYSIOTHERAPIST, NURSE)

13.3.1 {POTH} **Bosome miɛnsa a atwa mu yi wakɔhunu aban ayaresabea mu adwumayɛfoɔ no bi?**

Dabi	0
Aane	1

IF NO SKIP TO 13.4

13.3.2 {PTCARE} **Adamfoɔ anaa busuani bi dii wakyi kɔɛ?**

Dabi	0
Aane	1

Sɛ wokɔ baako biara a...

13.3.3 {POTTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde duru hɔ? (Sima Sɛn)**

MV=9999

13.3.4 {POTTRCST) **Ɛka sɛn na wobɔ ansa na wa duru hɔ?**

MV=9999

13.3.5 {POSTMINS} **Sɛ wohunu dɔkta noa, ɛmerɛ dodoɔ sɛn na wodi wɔ ne nkyɛn? (Sima Sɛn)**

MV=999

13.3.6 {POTCOST} **Ɛka dodoɔ sɛn na wobɔ na wotua ma hwɛ a dɔkta hwɛɛ wo no?**

MV=99999

13.3.7 {POTVIS} **Bosome miɛnsa ntam yi no, mperɛ dodoɔ sɛn na w'akɔ hunu dɔkta?**

MV=99

B: AYARESABEA ƐNHYƐ ABAN ASE PRIVATE HEALTH CARE PROVIDERS

Bosome miɛnsa a atwa mu yi wakɔ ayaresabea a ɛnhyɛ aban ase yi bi mu?

13.4 DƆKTA ƆNHYƐ ABAN ASE PRIVATE DOCTOR

13.4.1 {PPD}

Wone dɔkta bi a ɔnhyɛ aban ase bi anya nkitahodie bi bɛyɛ bosome miɛnsa aatwam mu yi?

Dabi 0
Aane 1

IF NO SKIP TO 13.5

13.4.2 {PPDCARE} **Adamfoɔ anaa busuani bi dii wakyi kɔɛ?**

Dabi 0
Aane 1

Sɛ wokɔ baako biara a...

13.4.3 {PPDTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde duru hɔ? (Sima Sɛn)**

MV=9999

13.4.4 {PPDTRCST) **Ɛka sɛn na wobɔ ansa na wa duru hɔ?**

MV=9999

13.4.5 {PPDMINS} **Sɛ wohunu dɔkta noa, ɛmerɛ dodoɔ sɛn na wodi wɔ ne nkyɛn? (Sima Sɛn)**

MV=999

13.4.6 {PPDCOST} **Ɛka dodoɔ sɛn na wobɔ na wotua ma hwɛ a dɔkta hwɛɛ wo no?**

MV=99999

13.4.7 {PPDVIS} **Bosome miɛnsa ntam yi no, mperɛ dodoɔ sɛn na w'akɔ hunu dɔkta?**

MV=99

13.5 ƐSE HO SIESIE - DENTISTRY

13.5.1 {PDNT}

Bosome miɛnsa a atwam yi wone dɔkta a ɔhwɛ ɛsee anya nkitahodie bi?

Dabi 0
Aane 1

IF NO, SKIP TO 13.6

13.5.2 {PDENCARE) **Adamfoɔ anaa busuani bi dii wakyi kɔɛ?**

Dabi 0
Aane 1

Sɛ wokɔ baako biara a...

13.5.3 {PDENTRMI} **Ɛmerɛ dodoɔ sɛn na wɔde duru hɔ? (Sima Sɛn)**

MV=9999

13.5.4 {PDENTRCT) **Ɛka sɛn na wobɔ ansa na wa duru hɔ?**

MV=9999

13.5.5 {PDENMINS} **Sɛ wohunu dɔkta noa, ɛmerɛ dodoɔ sɛn na wodi wɔ ne nkyɛn? (Sima Sɛn)**

MV=999

13.5.6 {PDENCOST} **Ɛka dodoɔ sɛn na wobɔ na wotua ma hwɛ a dɔkta hwɛɛ wo no?**

MV=99999

13.5.7 {PDENVIS} **Bosome miɛnsa ntam yi no, mperɛ dodoɔ sɛn na w'akɔ hunu dɔkta?**

MV=99

13.6 ƆDINSINI - TRADITIONAL HEALER

13.6.1 (World Health Organisation) **Bosome miɛnsa a atwamu yi wone dunsini bi anya nkitahodie bi?**

Dabi 0
Aane 1

IF NO SKIP TO 13.7

13.6.2 {PTHCARE) **Adamfoɔ anaa busuani bi dii wakyi kɔɛ?**

Dabi 0
Aane 1

Sɛ wokɔ baako biara a…

13.6.3 {PTHTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde duru hɔ? (Sima Sɛn)**

MV=9999

13.6.4 {PTHTRCST) **Ɛka sɛn na wobɔ ansa na wa duru hɔ?**

MV=9999

13.6.5 {PTHMINS} **Sɛ wohunu dunsini noa, ɛmerɛ dodoɔ sɛn na wodi wɔ ne nkyɛn? (Sima Sɛn)**

MV=999

13.6.6 {PTHCOST} **Ɛka dodoɔ sɛn na wobɔ anaa wotua ma hwɛ a dunsini hwɛɛ wo no?**

MV=99999

13.6.7 {PTHVIS} **Bosome miɛnsa ntam yi no, mperɛ dodoɔ sɛn na w'akɔ hunu dunsini?**

MV=99

13.7 AYARESABEA NSOM - HOSPITAL SERVICES

13.7.1 {PHOSAD} **Bɛyɛ bosome miɛnsa a atwamu yi yagye wo ato ayaresabea?**

Dabi 0
Aane 1

IF NO SKIP TO 13.8

13.7.2 {PHOSDAY} **Wodaa hɔ anadwo dodoɔ sɛn?** MV=99

13.7.3 {PHOSCOST} **Ka sɛn na wobɔ yɛ wɔ da a wodaa hɔ no nti?**

MV=99999

13.8 ADURO FA / MA MEDICATION

13.8.1 {PMEDS} **Bosome miɛnsa a atwamu yi woafa aduro bi?**

Dabi 0
Aane 1

IF NO SKIP TO 13.9

13.8.2 {PMEDCOST} **Aduro no boɔ kɔsii sɛn?**

MV=99999

13.9 APƆMUDEN INSHƆƆRANSE - HEALTH INSURANCE

13.9.1 {PMEDS} **Wo wɔ apɔmuden inshɔɔranse?**

Dabi 0
Aane 1

IF NO SKIP TO 14

13.9.2 {PINSCOVE} **Wo apɔmuden inshɔɔranse no kata whan nom so?**

Me nkoa 1
Me ne abusuafoɔ aka no nyinaa 2

13.9.3 {PINSCOST} **Sika sɛn na wotua wɔ apɔmuden inshɔɔranse no ho?**

(Code the price paid)

---

14 CONFIDENCE IN DATA

14.1 {PRFRATE}
Overall Rating of confidence in Data:

Reasonable (interviewee gave properly considered answers to more or less all questions) 0
A few doubts 1
Moderate doubts 2
Grave doubts (interviewer considered that the interviewee were unable/unwilling to give properly considered answers to most questions) 3
Worthless (more or less random answers) 4

Appendix K: Socio-demographic and Risk Factor Questionnaire II (Twi)

10/66 Awirefire Ho Nhwehɛmu Kuo	Dementia Research Group
Nnipa no Ho Nsɛm Nhwehwɛmu	Population-Based Study
Ɔpɛpon 2015	January 2015

Socio-Demographic and Risk Factor Questionnaire

INFORMANT VERSION

THE INFORMANT VERSION OF THIS QUESTIONAIRE ONLY NEEDS TO BE USED IF

A) IT IS IMPOSSIBLE TO GET THE INFORMATION FROM THE PARTICIPANT AND THE PARTICIPANT VERSION HAS NOT BEEN COMPLETED, OR

B) THE INTERVIEW IS WORRIED ABOUT THE RELAIABILITY OF THE INFORMATION FROM THE PARTICIPANT AND WANTS TO GET INFORMATION FROM THE INFORMANT ALSO

---

1. IDENTIFIERS

1.1 Ɛdaa nkɔmodie yi kɔɔ so: {DATE} ‹dd/mm/yy›

Enter date as day/month/year, e.g. <05/10/2003>

1.2 Ɔrebisa nsɛm no ahyɛnso nɔma: {INTERNID}

Interviewer ID number:

1.3 Abusua kuo ahyɛnso nɔma: {HOUSEID}

Household ID number:

1.4 Obi a ɔka dwumadie yi ho ahyɛnso nɔma: {PARTICID}

Participant ID number:

2.1 {IINTER}

This sociodemographic/ risk factor interview was conducted with:

Subject and informant	1
Informant only	2

2.2 {IRELAT} **Opanin/Ɔbaapanin (xxxx) yɛ wodeɛn?**

Ɔhokani	1
Ba Baa/Barima	2
Asew Barima/Baa	3
Nua	4
Busuani	5
Adamfo	6
Yɛte bɛn nanso kyɛnyɛn abusua	7
Foforɔbi	8
Me nim	9

---

3. EARLY LIFE

3.1 {ILIVED} **Ɛnfie dodoɔ sɛn na wo (xxxx) atena kuro yi mu?**

3.2 {IBORN} **Ɛhen na wɔwoo wo (xxxx)**

Kuro Kɛseɛ	0
Kuro Ketewa	1
Akuraa	2

3.3 {IMIDLIFE} **Ɛfiri emfie aduonu kɔsi aduosia mu no ɛhen na wo (xxxx) tenaa kɛse?**

Kuro Kɛseɛ	0
Kuro Ketewa	1
Akuraa	2

3.4 {ILATLIFE} **Ɛfiri ɛmfie aduosia rekɔ no ɛhen na wo (xxxx) atena kɛse?**

Kuro Kɛseɛ	0
Kuro Ketewa	1
Akuraa	2

3.5 {IEDUC} **Wo (xxxx) kɔɔ sukuu duru ɛhen?**

W'ankɔ bi	1
Kɔɔ kakra nanso wanwie pramiri sukuu	2
Wiee pramiri sukuu	3
Wiee sekandiri sukuu	4
Wiee college	5

3.6 {IREAD} **Wo (xxxx) tumi kenkan dawubɔ krataa?**

Dabi	0
Aane	1

3.7 {IWRITE} **Na wo (xxxx) tumi twerɛ krataa?**

Dabi	0
Aane	1

---

4. CURRENT CIRCUMSTANCES

4.1 {IHEADHSE} **Wo (xxxx) ne abusua kuo yi ti?**

Dabi	0
Aane	1

IF YES SKIP TO 4.3

4.2 {IREL} **Abusua kuo yi ti no yɛ wo (xxxx) deɛn?**

Hokani	1
Ba Barima/Baa,	2
Asew Barima/Baa	3
Nua Barima/Baa	4
Busuani	5
Adamfoɔ	6

4.3 {IMARRY} **Seisei yi wo (xxxx) aware?**

Ɔnnwaree da	1
W'aware/Ne obi te hɔ	2
Ɔyɛ kuna foɔ	3
W'agyae Awadeɛ	4

4.4 {IRELIG} **Wo (xxxx) ka ɛsom bi ho?**

Agnostic/Atheist	0
Roman Catholic	1
Anglican/Protestant	2
Other Christian	3
Jewish	4
Muslim	5
Buddhist	6
Hindu	7
Other (Inc. Traditional/Spiritual)	8

4.5 {IGOCHCH} **Wo (xxxx) kɔ ɛsom bi nhyiamu?**

Dabi	0
Aane dabiara	1
Aane dakoro dakora bi	2

4.6 {ICLUBS} **Wo (xxxx) kɔ manse nhyiamu die anaa nhyiamu bi tese ekuo?**

Dabi	0
Aane dabiara	1
Aane dakoro dakora bi	2

---

5. SOCIAL NETWORK

5.1 {IRELDIST} **Bɛbia wo (xxxx) te no nebusuani a ɔbɛn no paa no temu twe?**

Ɛfie korɔ mu/kwansin baako	1
Kwansin baako kɔsi num	2
Kwansin nsia kɔsi dunum	3
Kwansin dunsia kɔsi aduonum	4
Ɛboro kwansin aduonum	5

5.2 {ISIBDIST} **Ɛhen na wo (xxxx) nua baa/barima te?**

Onni nua	0
Ɛfie korɔ mu/kwansin baako	1
Kwansin baako kɔsi num	2
Kwansin nsia kɔsi dunum	3
Kwansin dunsia kɔsi aduonum	4
Ɛboro kwansin aduonum	5

5.3 {ICH} **Wo (xxxx) wɔ mma?**

Dabi	0
Aane	1

IF NONE SKIP TO 5.6

5.4 {ICHDIST} **Wo (xxxx) ba nea ɔte bɛn no paa no te hen?**

Onni mma	0
Ɛfie korɔ mu/kwansin baako	1
Kwansin baako kɔsi num	2
Kwansin nsia kɔsi dunum	3
Kwansin dunsia kɔsi aduonum	4
Ɛboro kwansin aduonum	5

5.5 {IRELFRQ} **Ɛmperɛ dodoɔ sɛn na wo (xxxx) hunu ne mma anaa abusuafoɔ bi ne wɔn kasa?**

Wɔnya bi koraa	0
Dabiara	1
Mperɛ nu kɔsi mprɛnsa nnawɔtwe biara	2
Anyɛ koraa no nnawɔtwe biara	3
Anyɛ koraa no bosome biara	4
Ɛnntae nse	5

5.6 {IFRD} **Wo (xxxx) wɔ namfo wɔ mpɔtam ha?**

Dabi	0
Aane	1

IF YES SKIP TO 5.10

5.7 {IFRDFRQ} **Ɛmperɛ dodoɔ sɛn na wo (xxxx) ne nadamfo bi di nkɔmɔ anaa ne no yɛ biribi?**

Onni namfo/ɛnsii da	0
Dabiara	1
Mperɛ nu kɔsi mprɛnsa nnawɔtwe biara	2
Anyɛ koraa no nnawɔtwe biara	3
Anyɛ koraa no bosome biara	4
Ɛnntae nse	5

5.8 {IFRDNUM} **Wo (xxxx) nnamfo a ɔbɛn no mu neɛhen na ɔtaa ne wɔn hyia? (At least a month) Wɔn din a edikan ne sɛn (e.g. Peter, Koo,)**

Code number of friends positively identified

5.9 {IFRDSAT}
This question is not asked to the informant?

5.10 {INEIFRQ} **Ɛmperɛ dodoɔ sɛn na wo (xxxx) ne wɔn a wɔte borɔno no so di nkɔmɔ anaa yɛ biribi?**

Ɛbi nnihɔ	0
Dabiara	1
Mperɛ nu kɔsi mprɛnsa nnawɔtwe biara	2
Anyɛ koraa nonnawɔtwe biara	3
Anyɛ koraa nobosome biara	4
Ɛnntae nse	5

5.11 {INEINUM}

Wo (xxxx) afipamfuɔ dodoɔ sɛn na wɔne wɔn hyia di nkɔmɔ?
(At least a month) Wɔn din a edikan de sɛn (e.g. John, Mr. Coffie)

Code number of neighbours identified

CONTINUE TO NEXT SHEET FOR SOCIOECONOMIC STATUS

---

6. SOCIO-ECONOMIC STATUS

6.1 {IJOB} **Wo (xxxx) wɔ adwuma?**

Adwuma ɔyɛ no ɛmerɛ biara	1
Adwuma a wɔnyɛ no dabiara	2
Ɛnii adwuma	3
Adesua ni	4
Ɔbaa/Barima warefoɔ	5
Ɔwɔ ahomegyɛ mu	6

6.2 {IJOBCAT} **Adwuma papa paa bɛn na wo (xxxx) ayɛ pɛn? Na adwuma bɛn na wo (xxxx) yɛ wɔ mu?**

Adwuman panin - Manager/Administrator	1
Nimdefoɔ a ɔwɔ ebia Apɔmuden, Adekyerɛ, Mmara anaa Sikasɛm mu–Professional (e.g. health, teaching, legal, financial)	2
Nimdefoɔ foforɔ wɔ Mfidie Nsiesie, Nɛɛse Adwuma anaa Adwinnie mu –Associate Professional (e.g. Technical, nursing, artistic)	3
Ɔfese Adwumayɛni/ɔtwerɛtwerɛfo - Clerical Worker/Secretary	4
Sotɔɔ Hwɛfoɔ–Shopkeeper	5
Nsaanodwumayɛni wɔ Adansie anaa Anyinam ahɔden Dwumadie mu –Skilled labourer (e.g. building, electrical etc.)	6
Nsaanodwuma mu boafoɔ – Semi–Skilled Labourer (e.g. Helper of Skilled Labourer)	7
Ɔnni Nsaanodwuma – Unskilled labourer	8
Kuadwuma mu Odwumayɛni – Agriculatural Worker	9
Missing Value	99

6.3 {ICJOBCAT} **Adwuma papa paa bɛn na wo (xxxx) hokani yɛɛ da?**

Adwuma bɛn na wɔyɛɛ yɛ wɔ saa adwuma no mu?

Adwuman panin - Manager/Administrator	1
Nimdefoɔ a ɔwɔ ebia Apɔmuden, Adekyerɛ, Mmara anaa Sikasɛm mu–Professional (e.g. health, teaching, legal, financial)	2
Nimdefoɔ foforɔ wɔ Mfidie Nsiesie, Nɛɛse Adwuma anaa Adwinnie mu –Associate Professional (e.g. Technical, nursing, artistic)	3
Ɔfese Adwumayɛni/ɔtwerɛtwerɛfo - Clerical Worker/Secretary	4
Sotɔɔ Hwɛfoɔ–Shopkeeper	5
Nsaanodwumayɛni wɔ Adansie anaa Anyinam ahɔden Dwumadie mu	

–Skilled labourer (e.g. building, electrical etc.) 6
Nsaanodwuma mu boafoɔ – Semi-Skilled Labourer (e.g. Helper of Skilled Labourer) 7
Ɔnni Nsaanodwuma – Unskilled labourer 8
Kuadwuma mu Odwumayɛni – Agriculatural Worker 9
Missing Value 99

6.4 {IINCOME} **Wo (xxxx) gye sika bi sɛ ɛyɛ pɛnhyɛn anaa akatua foforɔ bi?**

Dabi 0
Aane 1

Wonya sika, bɔtom sika anaa mfasoɔ bi?

Aban pɛnhyɛn – Government pension 1
Ankorankoreɛ pɛnhyɛn – Occupational pension 2
Ɛdɛmdie pɛnhyɛn anaa mfasoɔ bi – Disability pension/benefit 3
Sika a ɛfiri abusuafoɔ hɔ – Money from family 4
Sika a ɛfiri ɛdan a wɔde ahane mu – Income from rented land/property 5
Sika a ɛfiri adwuma akatua mu – Income from paid work 6
Afoforɔ bi – Other 7
Sika foforɔ biara nni hɔɔ – No further benefit 9

Type of benefit

6.5{IBTYPE1} # **6.6** {IBEN1} ####
6.7{IBTYPE2} # **6.8** {IBEN2} ####
6.9{IBTYPE3} # **6.10**{IBEN3} ####
6.11{IBTYPE4} # **6.12**{IBEN4} ####

---

7. APƆMUDEN HEALTH

7.1 {ITOLDP} **Yaka akyerɛ wo (xxxx) da sɛ wɔwɔ mogya borosoɔ?**

Dabi 0
Aane 1

IF NO, SKIP TO 7.5

7.2 {IBPYEAR} **Berɛ bɛn na edi kan a yɛka kyerɛɛ no?**

Mfie num a atwa mu	1
Mfie num kɔsi dua atwa mu	2
Ɛboro mfie du nie	3

7.3 {IBPTREAT} **Yede wo (xxxx) too aduro so?**

Dabi	0
Aane	1

7.4 {IBPCON} **Wo (xxxx) da so nom aduro?**

Dabi	0
Aane	1

7.5 {ITOLDHRT} **Dɔkta aka akyere wo (xxxx) da sɛ wɔwɔ akoma yadeɛ?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.8

7.6 {IHRTYEAR} **Berɛ bɛn na edi kan a yɛ ka kyerɛ no?**

Mfie num a atwa mu	1
Mfie numkɔsi dua atwa mu	2
Ɛboro mfie du nie	3

7.7 {IHRTWHAT} **Na dɔkta no se ɛyɛ deɛn?**

Heart Attack	1
Angina (Ɛyɛa wo bo twetwe wo, a ɛyɛ wo ya paa/ɛyea wo bo so yɛ wo tesɛ deɛ y'aso mu twe?)	2
Heart Failure	3
Valve disease	4
Other – Bibi wɔhɔ a yɛnbɔɔ su	5

7.8 {ICVA} **Wo (xxxx) anya stroke da a ɛhiaa sɛ dɔkta bɛhwɛ no? Ɛkɔsii sɛn?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.10

7.9 {ICVADIAG} **Hwan na hwehwɛɛ saa stroke no mu?**

Ɛnyɛ obiara	0
Dɔkta	1
Dɔkta nimdifoɔ bi	2

7.10 (Commonwealth Human Rights Initiative Africa) **Aba pɛn sɛ wo (xxxx) anya putupru apɔmu mmerɛ, ɔntumi nkasa anaa sɛ ɔnhunu adeɛ papa a ankyɛ a bɛyɛ da baako pɛ?**

Dabi	0
Aane	1

7.11 {ILOC} **Aba pɛn sɛ wo (xxxx) anya pira kesɛɛ bi wo ne tiri a ɛmaa ɔtɔɔ mum?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.15

7.12. {ILOCHRS} **7.13.** {ILOCMINS}

Ɛmerɛ dodoɔ sɛn na wo (xxxx) ɔtɔre emum? (Dɔnhwirɛ anaa sema)

7.14 {ILOCAGE} **Saa berɛ no na wo (xxxx) adi mfie sɛn?**

7.15 {ITOLDDM} **Obi aka akyerɛ wo (xxxx) sɛ wɔwɔ asikyire yadeɛ pɛn?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.17

7.16 {IDMTRT} **Wo (xxxx) hia aduane soronko bi, ɔnom enuro anaa wɔwɔ paneɛ?**

Aduane nkoa	1
Wɔnom aduro	2
Wɔbɔ paneɛ	3
Wɔnyɛ aduro biara	4

7.17 {ICOAD} **Sɛ aduru awɔberɛ a wo (xxxx) tae bɔ wa yi ahorɔ anɔpa?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.19

7.18 {ICOAD1} **Bosome dodoɔ sɛn na wɔyɛ adeɛ yi wɔ afe yi no mu?**

Ɛnnuru bosome miɛnsa	1
Bosome miɛnsa ne akyire	2

7.19 {IMAL} **Wo (xxxx) anya atiridie yadeɛ da? Ɛberɛ bɛn?**

Ɔnyaa bi da	0
Mfie num a atwam	1
Ɛboro mfie num nie	2

7.20 {ITB} **Wo (xxxx) abɔ nsamanwa da? Ɛberɛ bɛn a?**

Ɔnyaa bi da	0
Mfie num a atwam	1
Ɛboro mfie num nie	2

7.21 {ICYST} **Wo (xxxx) anya Cysticercosis da? Ɛberɛ bɛn?**

Ɔnyaa bi da	0
Mfie num a atwam	1
Ɛboro mfie num nie	2

7.22 {IPASTHX} **Ɛberɛ bi aba wɔ wo (xxxx) asetenamu a ne werɛ hooyɛ, anaa wɔyɛɛ dinn, anaa na n'ani ngye wɔ ɛneɛma bi te sɛ adwuma, agodie a ɛtwaa mu bɛyɛ ɛnawɔtwe mienu?**

Dabi	0
Aane	1

IF NO, SKIP TO 7.26

7.23 {IONSDEP} **Saa berɛ a edika no na wo (xxxx) adi mfie dodoɔ sɛn?**

MV=99

7.24 {IDOCRX} **Dɔkta a ɔhwɛ wo (xxxx) ne nabusuafoɔ anaa dɔkta bi a ɔhwɛ adwenemu yadeɛ bɛhwɛɛ no?**

Dabi	0
Aane	1

7.25 {IADMIT} **Yɛgyee wo (xxxx) no too ayaresabea a wɔhwɛ adwenemu yadeɛ?**

Dabi	0

Aane 1

7.26 {IFHDEM} **Nabusuafoɔ paa te sɛ nawɔfoɔ, anaa onuanom bi anya yadeɛ bi a ɔntumi nkae biribiara a ɛmaa no baa sɛ ɔntumi nhwɛ nehoo mpo?**

Dabi 0
Aane 1

IF NO, SKIP TO SECTION 8

7.26.1 {IFATHER} **Wɔpapa?**

Wanya bi 0
Aba kɔsɛm kyerɛ sɛ onyaa bi 1

Mfie a na wadi a ɛhyɛɛ aseɛ {IFATHAGE}

7.26.2 {IMOTHER} **Wɔ Maame?**

Wanya bi 0
Aba kɔsɛm kyerɛ sɛ onyaa bi 1

Mfie a na wadi a ɛhyɛɛ aseɛ {IMOTHAGE}

7.26.3 {ISIB1} **Onua (ɔbarima/ɔbaa)?**

Onua biara anya bi 0
Abakɔsɛm kyerɛ sɛ obi nyaa bi 1

Mfie a na wadi a ɛhyɛɛ aseɛ {ISIBAGE1}

7.26.4 {ISIB2} **Onua (ɔbarima/ɔbaa)**

Onua biara anya bi 0
Abakɔsɛm kyerɛ sɛ obi nyaa bi 1

Mfie a na wadi a ɛhyɛɛ aseɛ {ISIBAGE2}

7.26.5 {ISIB3} **Onua (ɔbarima/ɔbaa)**

Onua biara anya bi 0
Abakɔsɛm kyerɛ sɛ obi nyaa bi 1

Mfie a na wadi a ɛhyɛɛ aseɛ {ISIBAGE3}

7.26.6 {ISIB4} **Onua (ɔbarima/ɔbaa)**

Onua biara anya bi 0
Abakɔsɛm kyerɛ sɛ obi nyaa bi 1

Mfie a na wadi a ɛhyɛɛ aseɛ {ISIBAGE4}

---

8. IMPAIRMENT

8.1 Merebɛbobɔ nyarewa bi din na baako biara no mɛpɛsɛ wo bɛka akyerɛme sɛ ebia wo (xxxx) no wɔ saa yarewa no bi seisei anaa saa berɛ yi?

8.1.1 {IARTH} **Ahotutuo?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.2.1 {IEYE} **Aniyadeɛ?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.3.1 {IEAR} **Aso sie?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.4.1 {ICOUGH} **Ɛwa?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.5.1 {IRESP} **Krɔtoɔ?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.6.1 {IBP} **Mogya borosoɔ?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.7.1 {IHEAR} **Akoma yadeɛ?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.8.1 {IGUT} **Yafun yadeɛ?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.9.1{IFAINT} **Etwirɛ?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.10.1{ILIMB} **Stroke?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

8.11.1{ISKIN} **Honam ani yadeɛ a ɛnkudaa?**

IF YES

Kwan bɛn so na ɛha wo (xxxx) no?

Ɔnni saa yadeɛ no bi	0
Ɔwɔ bi nanso ɛnnha no	1
Ɔwɔ bi nanso ɛnnha no kɛse	2
Ɔwɔ bi na ɛha no yie paa	3

---
9. PAIN (YAW)

Questions 9.1 to 9.3 are not asked to the informant.

---
10. DISABILITY - DAS

10.1{IDASALL1} **Bɛyɛ sɛ bosome ni sɛn na wohunu wo (xxxx) apɔmuden?**

Ɛyɛ paa	0
Ɛyɛ	1
Ɛyɛ kakra	2
Ɛnyɛ	3
Ɛnyɛ koraa	4

Nsɛmmisa a edidisoɔ yi fa ɔhaw a ɛfa apɔmuden ho te sɛ yadeɛ, ɛpira, adwene mu, ɛna nsanom ne enuro nom.
To w'ani kɔ w'akyi bɛyɛ sɛ bosome ni na kyerɛ ɛhaw a wo (xxxx) faamu sɛ ɔyɛ saa neɛma yi a.

IN THE LAST 30 DAYS:

10.2: {IDAS1} **Sɛn na wo (xxxx) no berɛ sɛ ɔgyina nenanso kyɛre bɛyɛsɛ sima aduasa rekɔno a?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.3{IDAS2} **Sɛ wɔreyɛ nefie neɛma a?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.4{IDAS3} **Ɔresua adefoforɔ bi a?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.5{IDAS4} **Sɛ wobɛhyia ayɛ kwasafo adwuma anaa adeyɛ bi a obiara tumi yɛ?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.6{IDAS5} **Woyadeɛ ahano afa?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.7{IDAS6} **Wɔde n'adwene esi biribi so ayɛ atoaso bɛ sima du ɛ?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.8{IDAS7} **Ɔnante akɔ bɛyɛ kwansin baako suɛɛ?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.9{IDAS8} **Ɔredware ne ho ɛ?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.10{IDAS9} **Ɔresiesie ne ho ɛ?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.11{IDAS10} **Wɔne nnipa a wɔnnim wɔnom nhyiamu die?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so/ɔntumi nyɛ ne ho hwee koraa	4

10.12{IDAS11} **Ɛnamfofa so ɔtoa?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so / Ɔntumi nyɛ ne ho hwee koraa	4

10.13{IDAS12} **Daadaa dwumadie ne neɛma a wɔyɛ?**

Onni haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesɛɛ	2
Ɔhaw kesɛɛ paa	3
Ɔhaw kesɛɛ a ɛboro so / Ɔntumi nyɛ ne ho hwee koraa	4

10.14{IDASALL2} **Nsusansoɔ a saa ɔhaw yi nyaa wɔ n'abrabɔ so?**

W'anya haw	0
Ɔhaw ketewaa bi	1
Ɔhaw kesεε kakra	2
Ɔhaw kesεε paa	3
Ɔhaw kesεε a εboro so / Ɔntumi nyε ne ho hwee koraa	4

10.15{IDASALL3}

Bosome a atwamu yi, εnagyemanna dodoɔ sεn na saa εhaw yi kɔɔ so?
MV=99

10.16{IDASALL4} Na onntumi nnyε neεma a ɔtaa yε koraa εnam yadeε no nti? **MV=99**

10.17{IDASALL5} **Na sε woyi εnna a na wɔyare a w'antumi anyε hwee no firi mu a, wɔtee dwumadie a ɔtae yε no so εnam yadeε bi nti?**
MV=99

11: REPRODUCTIVE HEALTH

{IGENDER} **Saa nsεεm misa nan yi kɔ ma εmaa nkoaa**

Enter the subject's gender here

Female	1
Male	2

IF M, SKIP TO SECTION 12

11.1{IMENARC} **Wo (xxxx) buu nensa a edikan no na w'adi mfie sεn?**

MV=99

11.2{ICHINO} **Ɔwoo mma sεn?**

MV=99

11.3{ICHIAGE} **Wo (xxxx) woo nabakan no, na w'adi mfie sεn?**

MV=99

11.4{IMENPAUS} **Wo (xxxx) hyεε aseε sε woretwa bra na w'adi emfie sεn?**

MV=99

---

12. BEHAVIOUR AND LIFESTYLES

12.1 SMOKING

12.1.1{ISMOKE} **Ɛberɛ bi abɛsen/atwa mu no, na (xxxx) nom** sigrɛte**, taa, abua, asera, anaa ɔtwii bonto?**

Dabi	0
Aane	1

IF NO, SKIP TO 12.2 IF YES

12.1.2{ISMOKE2} **Nea ɛwɔ he na wo (xxxx) nom yɛ?**

Sigrɛte	1
Taa	2
Abua	3
Asera	4
Bonto	5

12.1.3{ISTART} **Wo (xxxx) hyɛɛ aseɛ nom sigrɛte /taa/abua/asera anaa ɔtwii bonto no, na w'adi mfie sɛn?**

12.1.4{ISMKNOW} **Wo (xxxx) daso nom sigrɛte/taa/abua/asera anaa ɔtwii bonto?**

Dabi	0
Aane	1

IF YES, SKIP TO 12.1.6

12.1.5(Lauber & Rössler) **Wo (xxxx) gyae sigrɛte/taa/abua/asera nom anaa ɔtwi bonto no na wadi mfie sɛn? MV=99**

12.1.6{ICIGDOSE} **Sigrɛte dodoɔ sɛn na na wo (xxxx) nom anaa sɛ seisei wɔnom dakoro biara?**
MV=999

12.2 ALCOHOL

12.2.1{IALCPAST}
Ansa na wo (xxxx) edii mfie aduosia num no na nnawɔtwe biara no na wɔnom nsa dodoɔ bɛyɛ (maxi) **sɛn?** (Record maximum regular consumption in UNITS of alcohol per week)

1 Unit= Tɔmɛ baako
Nsa denden ketewaa bi
Wine tɔmɛ baako
32 Units = Nsa denden akɔtoa
999 = Me nim

12.2.2{IALCNOW} **Na wɔ boroo mfie aduosia num yi nsoɛ?**
1 Unit= Tɔmɛ baako
Nsa denden ketewaa bi
Wine tɔmɛ baako
32 Units = Nsa denden akɔtoa
999 = Me nim

IF NEVER A DRINKER SKIP TO 12.3

12.2.3{IHEAVY} **Ɛberɛ bi atwam a anka wo (xxxx) bɛka sɛ na wɔnom nsa kɛse paa?**

Dabi	0
Aane	1

12.2.4{IALCTRT} **Yapɛ aduro bi ama wo (xxxx) pɛn sɛdea ɛbɛma no agyae nsanom?**

Dabi	0
Aane	1

12.3 DIET

12.3.1{IMEATFRQ} **Mperɛ dodoɔ sɛn na wo (xxxx) we mogya nam?**

Wɔnwe koraa	0
Dakoro dakoro	1
Wɔtae we	2
Dabiara	3

12.3.2{IFISHFRQ} **Mperɛ dodoɔ sɛn na wo (xxxx) we nsuomu nam?**

Wɔnwe koraa	0
Dakoro dakoro	1
Wɔtae we	2
Dabiara	3

12.3.3{IVEGS} **Ɛbɛyɛ ɛnna miɛnsa ni mperɛ dodoɔ sɛn na wo (xxxx) adi aduaba ne nhaban ma?** (One fruit or one portion of salad or vegetables counts as a serving.
MV=99

12.3.4{IHUNDER} **Ɛkɔm tumi de wo (xxxx) ɛnam sɛ aduane ɛnni hɔ nti? Mperɛ dodoɔ sɛn na ɛba saa?**

Ɛnsii da	0
Ɛtɔ dabi ɛkɔm de no	1
Ɛkɔm ntaa nne no	2
Ɛkɔm di no dabiara	3

12.4. EXERCISE

12.4.1{IACTIVE} **Sɛ wohwɛ adwuma ne adagyeɛ a wɔnya a wobɛka sɛ wo (xxxx)**

Wɔ ahoɔden paa	1
Wɔ ahoɔden kakra	2
Nni ahoɔden papa	3
Nni ahoɔden koraa	4

12.4.2{IWALKANY} **Wo (xxxx) anante bɛyɛ sima du kɔpim dunum anaa kwansin fa bosome yi mu?**

Dabi	0
Aane	1

12.4.3{IWALKOFT} **MV=99**

Bosome a etwaa mu yi mperɛ dodoɔ sɛn na wo (xxxx) nantee bɛyɛ kwansin fa anaa sima du kɔpim dunum?

12.4.4{IPASTEX} **Wo (xxxx) taa tenetene napɔmu?**

Ɔyɛ sene nea na ɔyɛ mfie du a atwam no	3
Ɔyɛ tesɛɛ nea na ɔyɛ mfie du a atwam no	2
Ɔnyɛ enuru nea na ɔyɛ mfie du a atwam no	1

---

13. USE OF SERVICES

A. ABAN AYARESABEA NKUMAA ADWUMAYEFUƆ GOVERNMENT PRIMARY HEALTH CARE PROVIDERS

Ɛbɛyɛ abosome miɛnsa ni wo (xxxx) akɔ aban ayaresabea akɔhu dɔkta anaa ayaresabea adwumayɛfoɔ no bi?

13.1 AYARESAEA NKUMAA PRIMARY CARE

13.1.1{IPC} **Wo (xxxx) akɔ ayaresabea nkumaa yi bi mu bɛyɛ abosome miɛnsa ntam ni?**

Dabi	0
Aane	1

IF NO, SKIP TO 13.2

13.1.2{IPCCARE} **Adamfoɔ anaa busuani bi dii wo (xxxx) no akyi kɔɛ?**

Dabi	0
Aane	1

Sɛ wɔkɔ baako biara a:

13.1.3{IPCTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde tu kwan? (Sima Sɛn)**

13.1.4{IPCTRCST} **Ɛka sɛn na ɔbɔ de tu kwan?**

13.1.5{IPCMINS} **Sɛ ohunu dɔkta a merɛ dodoɔ sɛn na ode wɔ ne nkyɛn? (Sima Sɛn)**

13.1.6{IPCCOST} **Sika sɛn na otua ma ɛhwɛ a dɔkta hwɛ no no?**

13.1.7{IPCVIS} **Mperɛ dodoɔ sɛn na wɔkɔɔ wo bosome miɛnsa yi mu?**

13.2 ABAN AYARESABEA KESE DƆKTA GOVERNMENT HOSPITAL DOCTOR

13.2.1{IHOSP} **Bosome miɛnsa a atwa mu yi wo (xxxx) akɔhu dɔkta bi wɔ aban ayaresabea?**

Dabi 0
Aane 1

IF NO, SKIP TO 13.3

13.2.2{IHPCARE} **Adamfoɔ anaa busuani bi dii wo (xxxx) no akyi kɔ yɛ?**

Dabi 0
Aane 1

Sɛ wɔkɔ baako biara a:

13.2.3{IHPTRMIN} **Ɛmerɛ dodoɔ sɛn na wode tu kwan? (Sima Sɛn)**

13.2.4{IHPTRCST} **Ɛka sɛn na ɔbɔ de tu kwan?**

13.2.5{IHPMINS} **Sɛ ohunu dɔkta a merɛ dodoɔ sɛn na ode wɔ ne nkyɛn? (Sima Sɛn)**

13.2.6{IHPCOST} **Sika sɛn na otua ma ɛhwɛ a dɔkta hwɛ no no?**

13.2.7{IHPVIS} **Mperɛ dodoɔ sɛn na wɔkɔɔ wɔ bosome miɛnsa yi mu?**

13.3 **ABAN AYARESABEA ADWUMAYEFUƆ FOFORO BI** OTHER GOVERNMENT HEALTH WORKER (EG PHYSIOTHERAPIST, NURSE)

13.3.1{IOTH} **Bosome miɛnsa a atwamu yi wo (xxxx) akɔ hu aban ayaresabea mu adwuma yɛfoɔ no bi? Foforo bi?**

Dabi 0
Aane 1

IF NO, SKIP TO 13.4

13.3.2{IOTCARE} **Adamfoɔ anaa busuani bi dii wo (xxxx) no akyi kɔ yɛ?**

Dabi 0
Aane 1

Sɛ wɔkɔ baako biara a:

13.3.3{IOTTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde tu kwan? (Sima Sɛn)**

13.3.4{IOTTRCST} **Ɛka sɛn na ɔbɔ de tu kwan?**

13.3.5{IOTMINS} **Sɛ ohunu dɔkta a merɛ dodoɔ sɛn na ode wɔ ne nkyɛn? (Sima Sɛn)**

13.3.6{IOTCOST} **Sika sɛn na otua ma ɛhwɛ a dɔkta hwɛ no no**

13.3.7{IOTVIS} **Mperɛ dodoɔ sɛn na wɔkɔɔ wɔ bosome miɛnsa yi mu?**

B. AYARESABEA ƐNHYƐ ABAN ASE PRIVATE HEALTH CARE PROVIDERS

Bosome miɛnsa a atwamu yi wo (xxxx) akɔ hu ayaresabea ɛnhyɛ aban ase mu adwuma yɛfoɔ no bi?

13.4 DƆKTA ƆNHYƐ ABAN ASE PRIVATE DOCTOR

13.4.1{IPD} **Wo (xxxx) ne dɔkta bi a ɔnhyɛ aban ase bi anya nkitahodie bi bɛyɛ bosome miɛnsaa atwamu yi mu?**

Dabi 0
Aane 1

IF NO, SKIP TO 13.5

13.4.2{IPDCARE} **Adamfoɔ anaa busuani bi dii wo (xxxx) no akyi kɔ yɛ?**

Dabi 0
Aane 1

Sɛ wɔkɔ baako biara a:

13.4.3{IPDTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde tu kwan? (Sima Sɛn)**

13.4.4{IPDTRCST} **Ɛka sɛn na ɔbɔ de tu kwan?**

13.4.5{IPDMINS} **Sɛ ohunu dɔkta a merɛ dodoɔ sɛn na ode wɔ ne nkyɛn? (Sima Sɛn)**

13.4.6{IPDCOST} **Sika sɛn na otua ma ɛhwɛ a dɔkta hwɛ no no**

13.4.7{IPDVIS} **Mperɛ dodoɔ sɛn na wɔkɔɔ wɔ bosome miɛnsa yi mu?**

13.5 ƐSE HO SIESIE DENTISTRY

13.5.1 {IDENT} **Bosome miɛnsa a atwamu yi wo (xxxx) ne dɔkta a ɔhwɛ ɛnsene anya nkitahodie bi?**

Dabi 0
Aane 1

IF NO, SKIP TO 13.6

13.5.2{IDENCARE} **Adamfoɔ anaa busuani bi dii wo (xxxx) no akyi kɔ yɛ?**

Dabi 0
Aane 1

Sɛ wɔkɔ baako biara a:

13.5.3{IDENTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde tu kwan? (Sima Sɛn)**

13.5.4{IDENTRCT} **Ɛka sɛn na ɔbɔ de tu kwan?**

13.5.5{IDENMINS} **Sɛ ohunu dɔkta a merɛ dodoɔ sɛn na ode wɔ ne nkyɛn? (Sima Sɛn)**
13.5.6{IDENCOST} **Sika sɛn na otua ma ɛhwɛ a dɔkta hwɛ no no**
13.5.7{IDENVIS} **Mperɛ dodoɔ sɛn na wɔkɔɔ wɔ bosome miɛnsa yi mu?**

13.6 ƆDINSINI TRADITIONAL HEALER

13.6.1{ITH} **Bosome miɛnsa a atwamu yi wo (xxxx) ne ɔdinsini bi anya nkitahodie bi?**

Dabi	0
Aane	1

IF NO, SKIP TO 13.7

13.6.2{ITHCARE} **Adamfoɔ anaa busuani bi dii wo (xxxx) no akyi kɔ yɛ?**

Dabi	0
Aane	1

Sɛ wɔkɔ baako biara a:

13.6.3{ITHTRMIN} **Ɛmerɛ dodoɔ sɛn na wɔde tu kwan? (Sima Sɛn)**

13.6.4{ITHTRCST} **Ɛka sɛn na ɔbɔ de tu kwan?**

13.6.5{ITHMINS} **Sɛ ohunu ɔdinsini na merɛ dodoɔ sɛn na ode wɔ ne nkyɛn? (Sima Sɛn)**
13.6.6{ITHCOST} **Sika sɛn na otua ma ɛhwɛ a ɔdinsini hwɛ no no**
13.6.7{ITHVIS} **Mperɛ dodoɔ sɛn na wɔkɔɔ wɔ bosome miɛnsa yi mu?**

13.7 AYARESABEA NSOM HOSPITAL SERVICES

13.7.1{IHOSAD} **Yagye wo (xxxx) ato ayaresabea bi wɔ bosome miɛnsa a atwamu yi?**

Dabi	0
Aane	1

IF NO, SKIP TO 13.8

13.7.2{IHOSDAY} **Ɔdaa hɔ anadwo dodoɔ sɛn?**

13.7.3{IHOSCOST} **Sɛn na motua yɛ wɔ da wɔ daa hɔno nti?**

13.8 ADURO FA/MA MEDICATION

13.8.1{IMEDS} **Wo (xxxx) afa aduro bi bosome miɛnsa a atwamu yi?**

Dabi 0

Aane 1

IF NO, SKIP TO 13.9

13.8.2{IMEDCOST} **Aduro no boɔ kosii sɛn?**

13.9 APƆMUDEN INSHƆƆRANSE HEALTH INSURANCE

13.9.1{IINSURA} **Wo (xxxx) wɔ apɔmuden inshɔɔranse?**

Dabi 0

Aane 1

IF NO, SKIP TO SECTION 14

13.9.2{IINSCOVE} **Wo (xxxx) apɔmuden inshɔɔranse no kata hwan nom?**

Me (xxxx) nkoa 1

Me (xxxx) ne abusuafoɔ a aka no nyinaa 2

13.9.3{IINSCOST} **Sika sɛn na wo (xxxx) tua wɔ apɔmuden inshɔɔranse no ho?**

---

14. CONFIDENCE IN DATA

14.1 {PRFRATE} Overall Rating of Confidence in Data:

Reasonable (interviewee gave properly considered answers to more or less all questions)	0
A few doubts	1
Moderate doubts	2
Grave doubts (interviewer considered that the interviewee was unable/unwilling to give properly considered answers to most questions)	3
Worthless (more or less random answers)	4

Appendix L: Topic Guide

GUIDANCE FOR KINTAMPO STUDY QUALITATIVE INTERVIEWS

Interview Guide for Household Case Studies (older person plus other household members involved in caregiving)

Thank you for agreeing to be interviewed.

"As you know, we are interested in finding out about the needs of [name of the older person] and how you as a household live together and take care of one another. We are particularly interested in how your family copes".

"In order to find out about this, I would like to do three things during the course of the interview. I will ask you about the relationships of important people in your family, I will also ask you to tell me about [name of older person] and how things have been for you and the rest of the family. Finally, I will ask you a few questions about what you have told me. At any time, please feel free to include anything that you feel is important".

"Does that sound OK"?

[1. MAPPING RELATIONSHIPS- USE FIGURE 1]

So, firstly, so that I can get an idea of the important people related to this family:

1. Could you tell me about who lives in your home (names, sex, relationship to you, birth year, employment, location)
2. Can you tell me about your parents, children and partner [if not living in the household]
3. Are there any people who have lived with you in the past 10 years who have since moved out or passed away?
4. Are there any people who you haven't mentioned and who do not live with you who are an important part of your life, or that of [name of older person]

[2. NARRATIVE- ***see notes below*****]**

So tell me about how things have been. When did you first start to notice changes in [older person's name] health?

[PROMPTS: and what happened after that/what happened next? And how have things been over the last year/months/weeks. How did that affect you/other people in the house?]

[Interviewer should make notes on Figure 2 about key events- changes in older person's health, changes in household circumstances and change in circumstance for interviewee]

[3. QUESTIONS- USE FIGURE 2]

[If not covered in main narrative] How did [event] affect your finances? How did [event] effect the family's finances?

[If not covered in main narrative] When [change **re**. care given to older person] happened, who decided that [change **re**. care given to older person] should happen? Did everyone agree that this was the best thing to happen?

[If not covered in main narrative] What were the reasons for [change **re**. care given to older person]? Were there financial considerations related to [change **re**. care given to older person]?

[If not covered in main narrative] Apart from what you have told me, is there anything else that has happened in the last 10 years that has had a significant impact upon the finances of the family? [Give examples if needed- someone being ill and therefore not being able to work, someone moving away from the house] [If yes] Could you tell me about that?

NOTES FOR INTERVIEWER

Text in [ ] is meant as guidance for the interviewer. All other text is meant as an outline script (i.e. to be said) to the interviewee.

2. **NARRATIVE**

As much as possible, avoid interrupting the participant's story. However, if they come to a pause, it may be helpful to prompt them to tell you "what happened next".

3. **QUESTIONS**

Refer to notes made on Figure 2 and prompt the participant for more information about important events using the suggested questions, if sufficient detail was not provided in the main narrative.

In particular, you may need to ask specific questions about decision making and stigma/discrimination in relation to all the important events discussed by the participant- if this is not covered in the main narrative.

Thank you very much for your answers so far. Now I want to ask you about something slightly different. I have asked you to tell me about [older person's] illness and how your family copes with this. I am interested to find out a few more things about your thoughts about [older person's] illness.

[Only ask following questions if not covered in main narrative]

What do you think has caused [older person's] problems?
Why do you think it started when it did?
How severe is the sickness? Will it have a long or short course?
What kind of treatment do you think [older person] should receive?
What are the most important results you hope to receive from this treatment?
What are the chief problems [older person's] sickness has caused for you?
What do you fear most about [older person's] sickness?

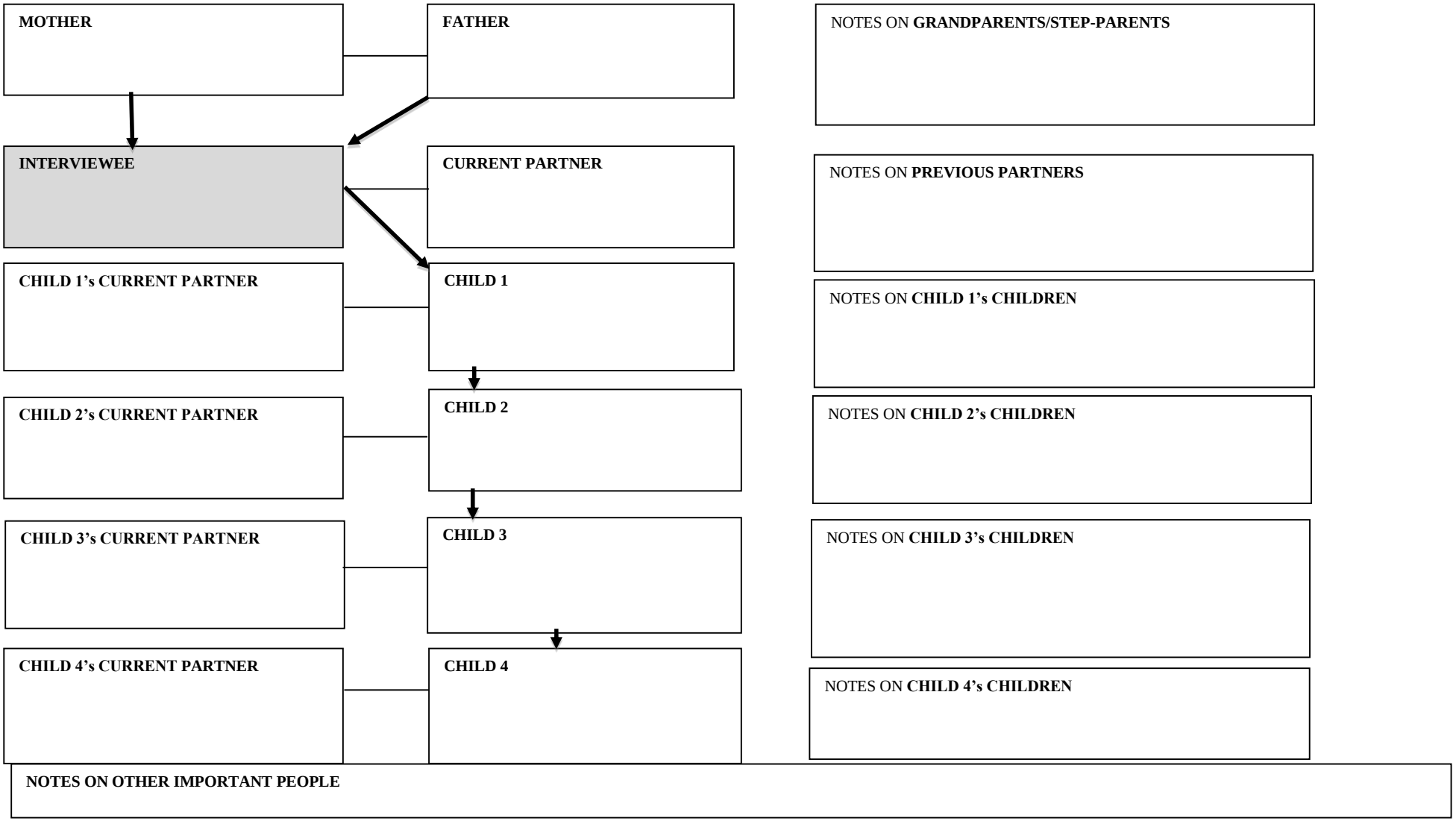
[If not covered in main narrative] Have you tried to get help for [older person]? [I.e. have you gone to traditional/religious healer, healthcare worker, and other person?] Can you tell me what happened? [Why you chose this person? Was the person helpful?]

[If not covered in main narrative] Have there been times when you have felt that people treated you differently/negatively because of [older person's] condition/behaviour? [I.e. by people we mean community members, family, neighbours, healthcare workers, shopkeepers etc.] Could you tell me a bit about these experience?

Appendix M: Relationship Mapping

Figure1. MAPPING RELATIONSHIPS

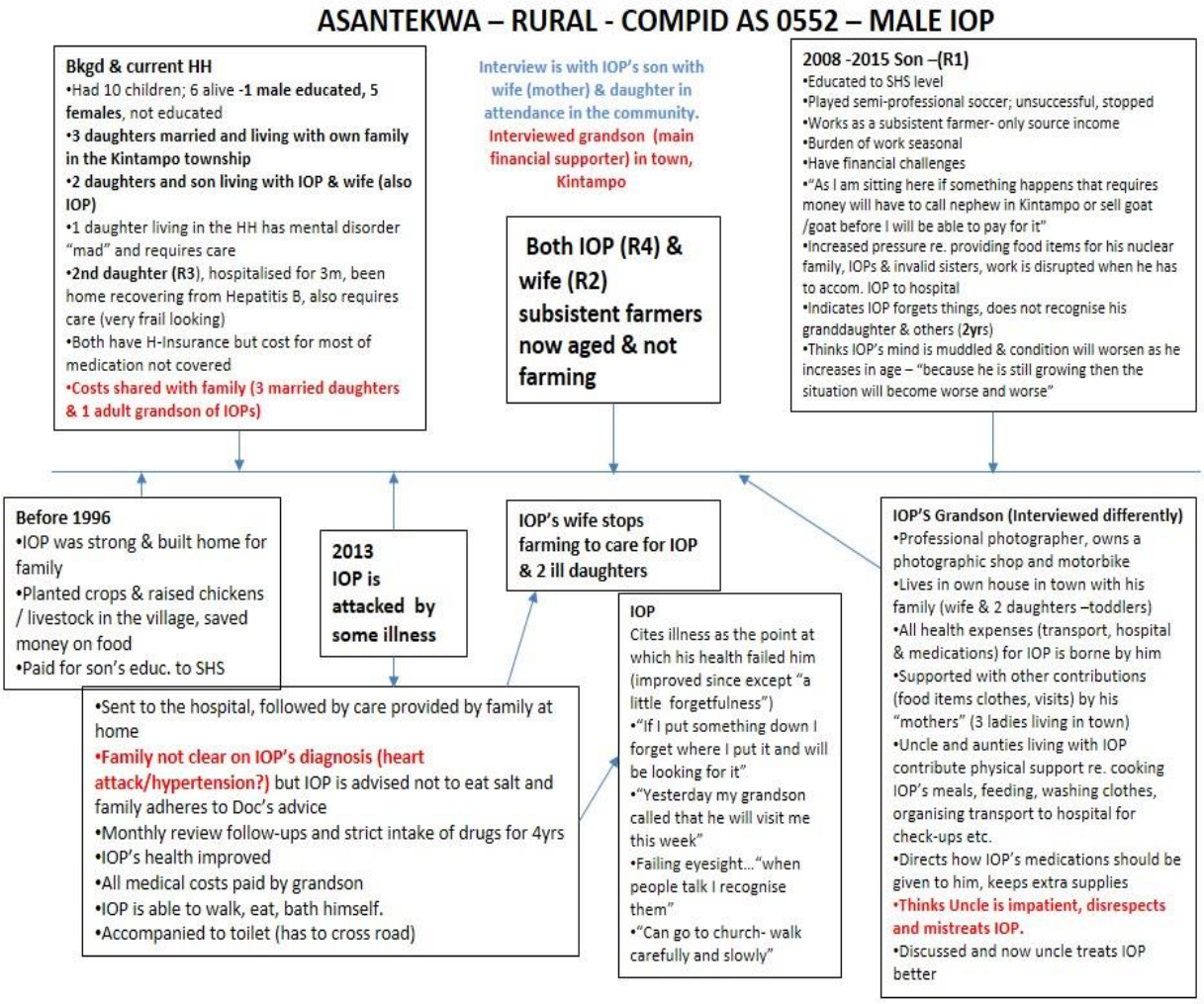
KEY: M=male F=female; NR=non-resident; D=died (include date)



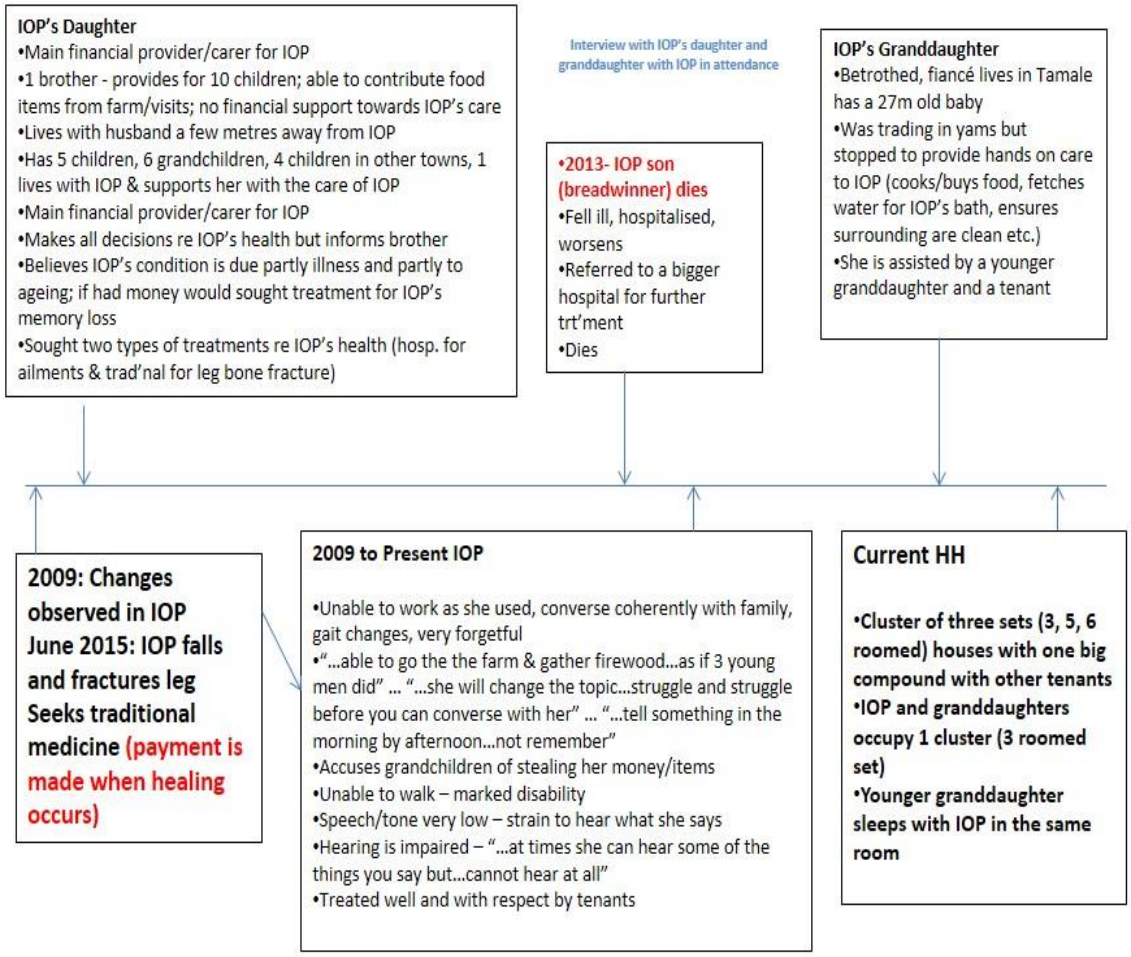
Appendix N: Timeline of Key Events

Year	Change in older person's health and functional status	Change in household circumstances	Change in circumstances of main carer

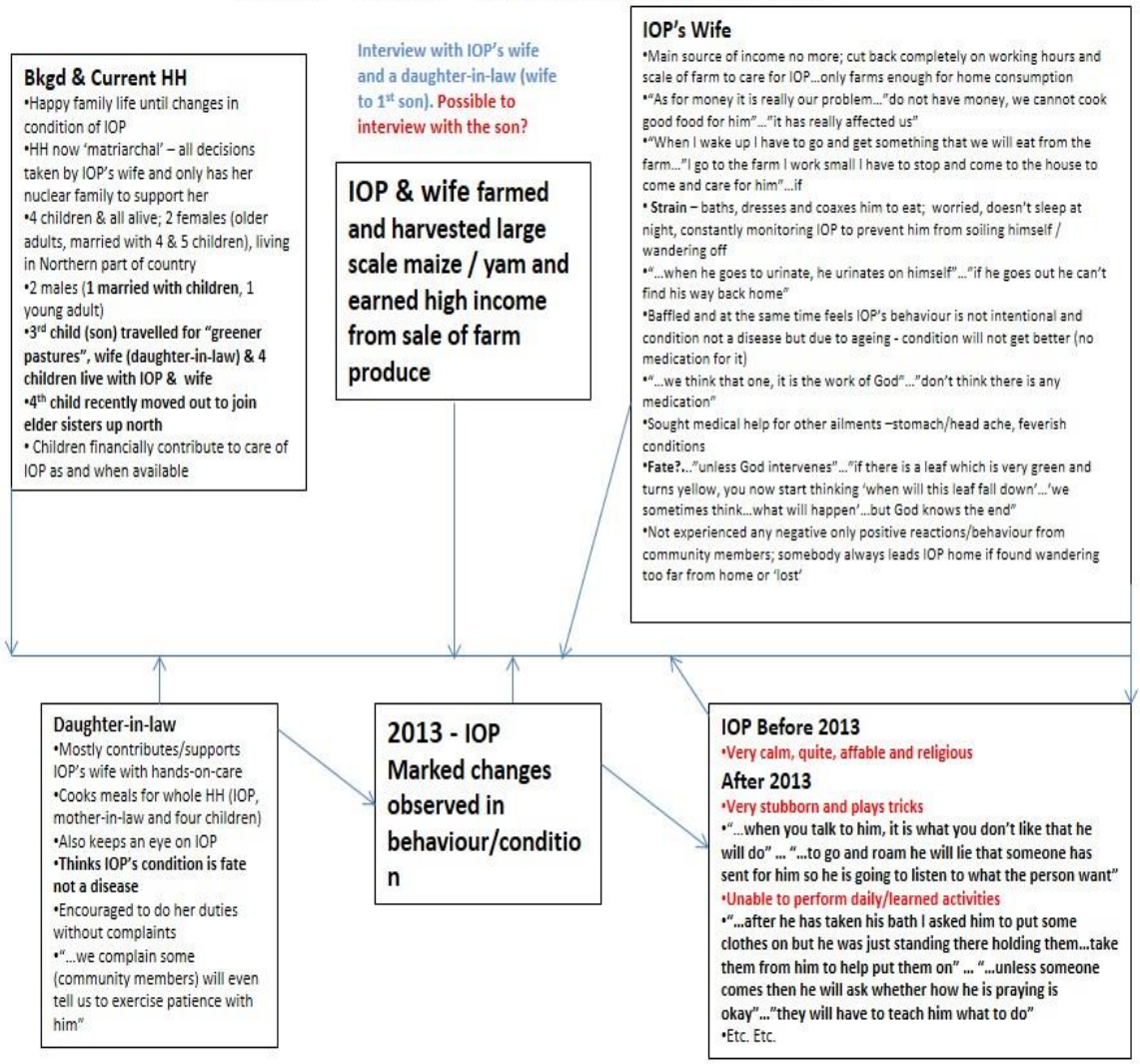
Appendix O: Summaries of Household Interviews



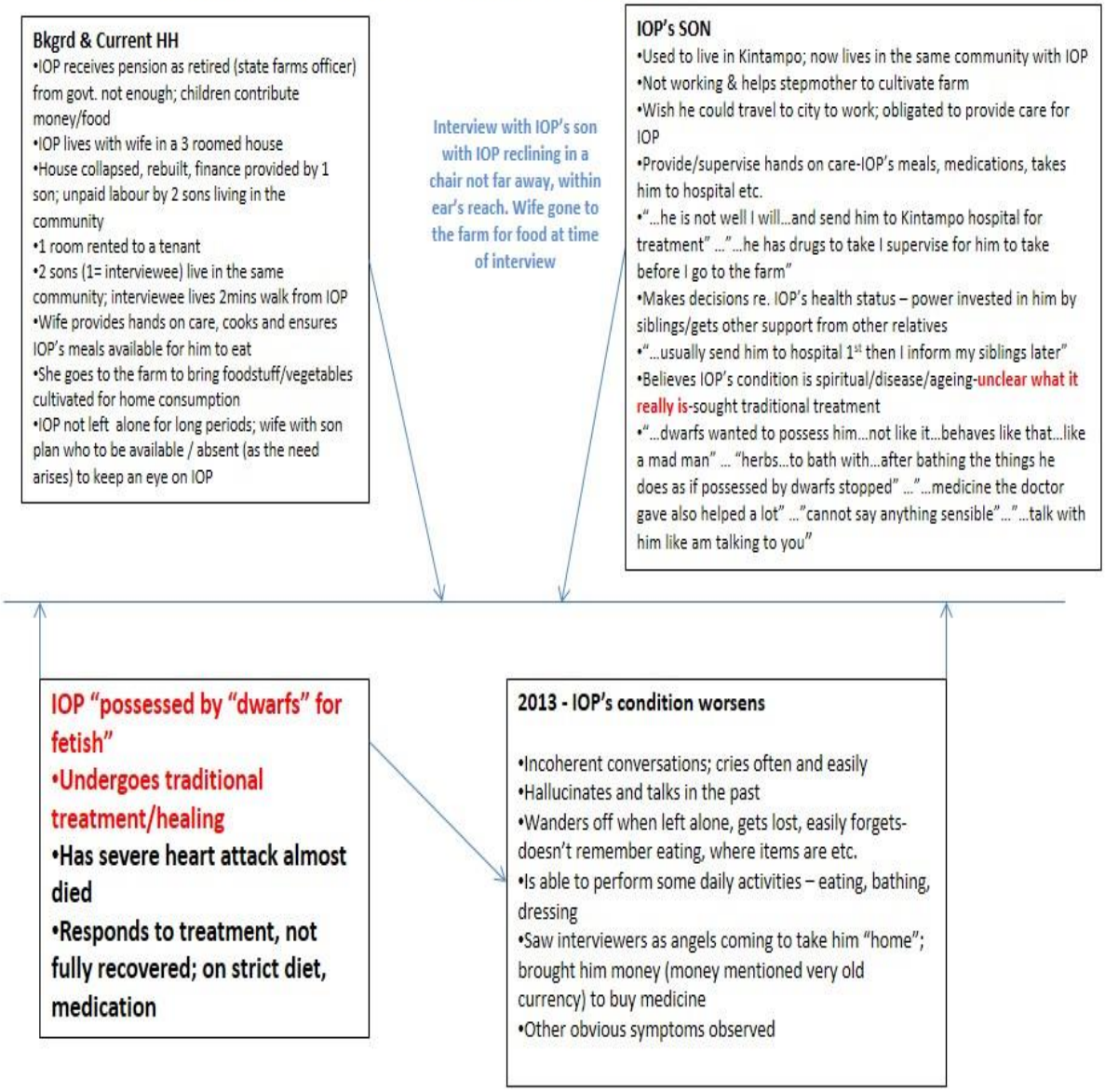
BABATOR - RURAL-COMPID – BB 0731 – FEMALE IOP

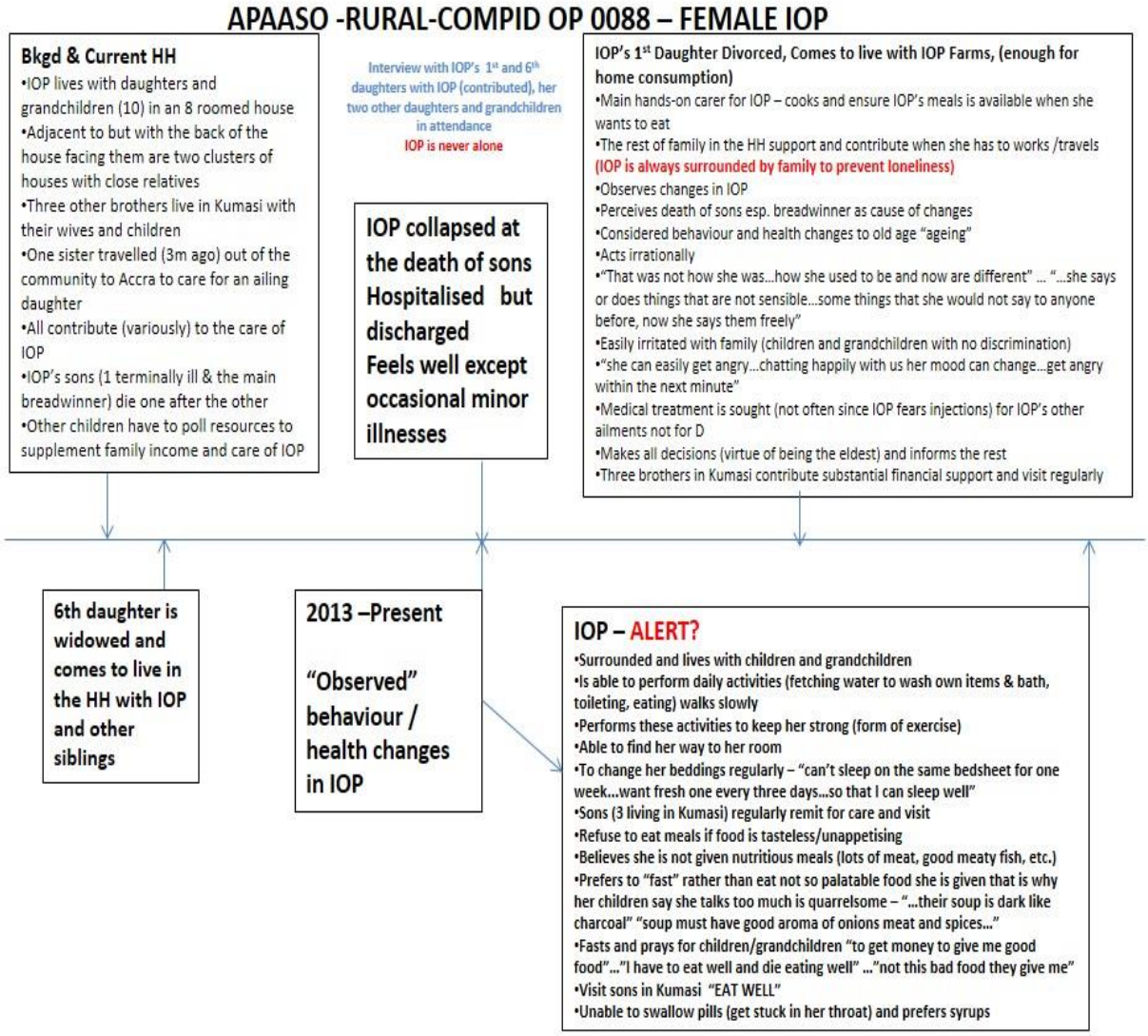


NANTE – RURAL – COMPID NN 0081- MALE IOP

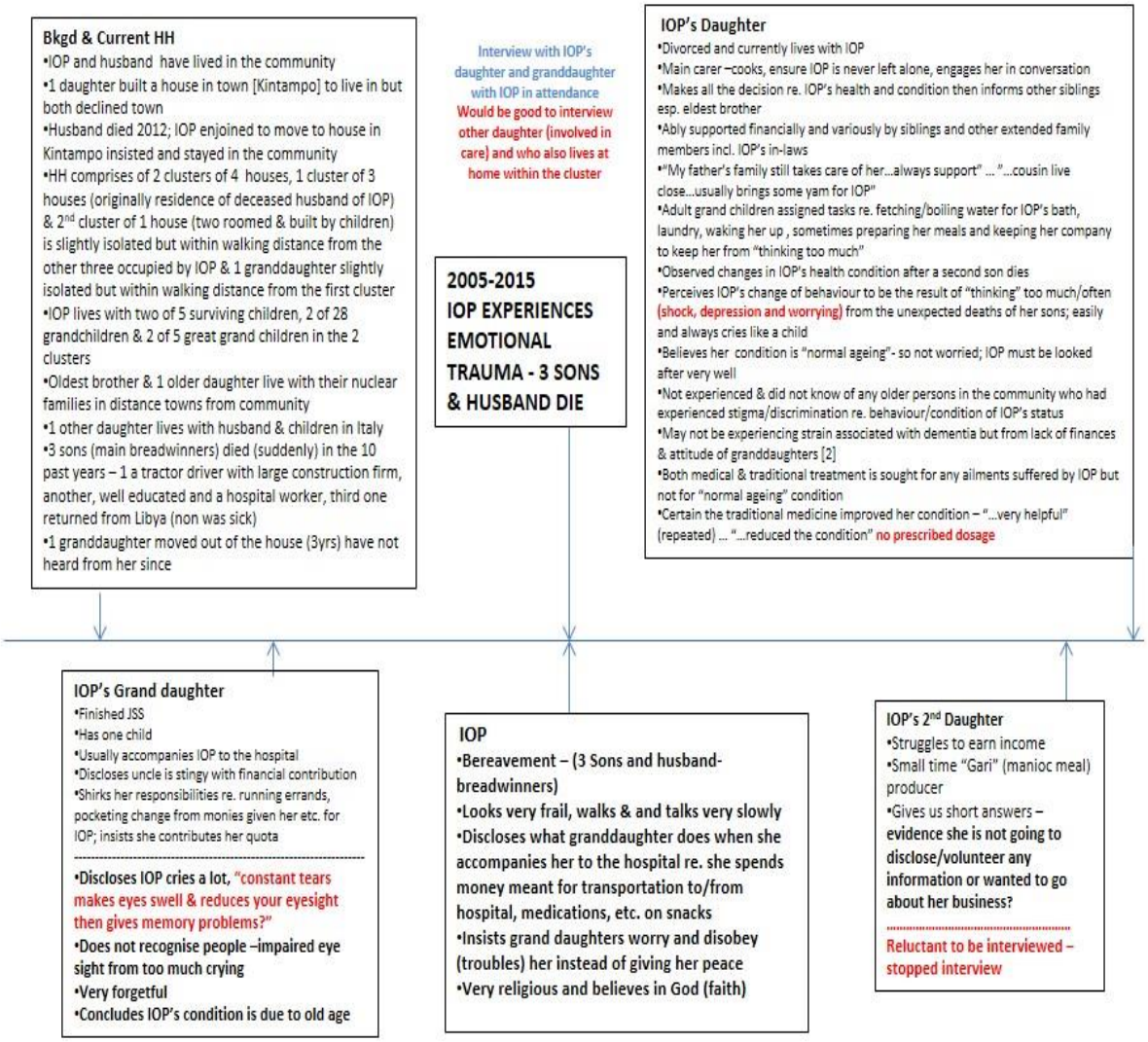


ASANTEKWA – RURAL - COMPID AS 0533 – MALE IOP

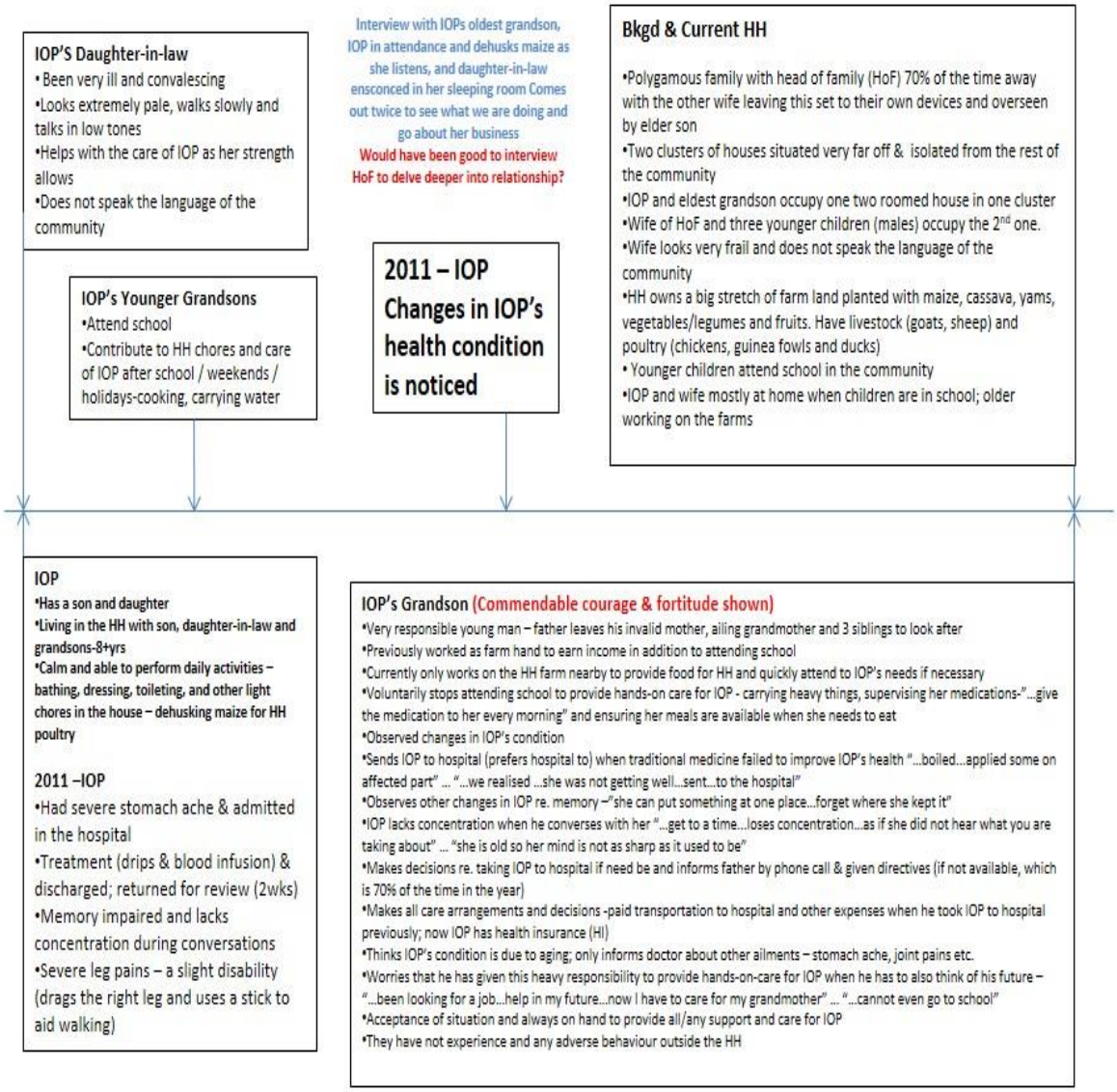



APAASO -RURAL-COMPID OP 0088 – FEMALE IOP
Bkgd & Current HH
•IOP lives with daughters and grandchildren (10) in an 8 roomed house
•Adjacent to but with the back of the house facing them are two clusters of houses with close relatives
•Three other brothers live in Kumasi with their wives and children
•One sister travelled (3m ago) out of the community to Accra to care for an ailing daughter
•All contribute (variously) to the care of IOP
•IOP's sons (1 terminally ill & the main breadwinner) die one after the other
•Other children have to poll resources to supplement family income and care of IOP
Interview with IOP's 1st and 6th daughters with IOP (contributed), her two other daughters and grandchildren in attendance
IOP is never alone
IOP collapsed at the death of sons
Hospitalised but discharged
Feels well except occasional minor illnesses
IOP's 1st Daughter Divorced, Comes to live with IOP Farms, (enough for home consumption)
•Main hands-on carer for IOP – cooks and ensure IOP's meals is available when she wants to eat
•The rest of family in the HH support and contribute when she has to works /travels
(IOP is always surrounded by family to prevent loneliness)
•Observes changes in IOP
•Perceives death of sons esp. breadwinner as cause of changes
•Considered behaviour and health changes to old age "ageing"
•Acts irrationally
•"That was not how she was…how she used to be and now are different" … "…she says or does things that are not sensible…some things that she would not say to anyone before, now she says them freely"
•Easily irritated with family (children and grandchildren with no discrimination)
•"she can easily get angry…chatting happily with us her mood can change…get angry within the next minute"
•Medical treatment is sought (not often since IOP fears injections) for IOP's other ailments not for D
•Makes all decisions (virtue of being the eldest) and informs the rest
•Three brothers in Kumasi contribute substantial financial support and visit regularly
6th daughter is widowed and comes to live in the HH with IOP and other siblings
2013 –Present
"Observed" behaviour / health changes in IOP
IOP – ALERT?
•Surrounded and lives with children and grandchildren
•Is able to perform daily activities (fetching water to wash own items & bath, toileting, eating) walks slowly
•Performs these activities to keep her strong (form of exercise)
•Able to find her way to her room
•To change her beddings regularly – "can't sleep on the same bedsheet for one week…want fresh one every three days…so that I can sleep well"
•Sons (3 living in Kumasi) regularly remit for care and visit
•Refuse to eat meals if food is tasteless/unappetising
•Believes she is not given nutritious meals (lots of meat, good meaty fish, etc.)
•Prefers to "fast" rather than eat not so palatable food she is given that is why her children say she talks too much is quarrelsome – "…their soup is dark like charcoal" "soup must have good aroma of onions meat and spices…"
•Fasts and prays for children/grandchildren "to get money to give me good food"…"I have to eat well and die eating well" …"not this bad food they give me"
•Visit sons in Kumasi "EAT WELL"
•Unable to swallow pills (get stuck in her throat) and prefers syrups

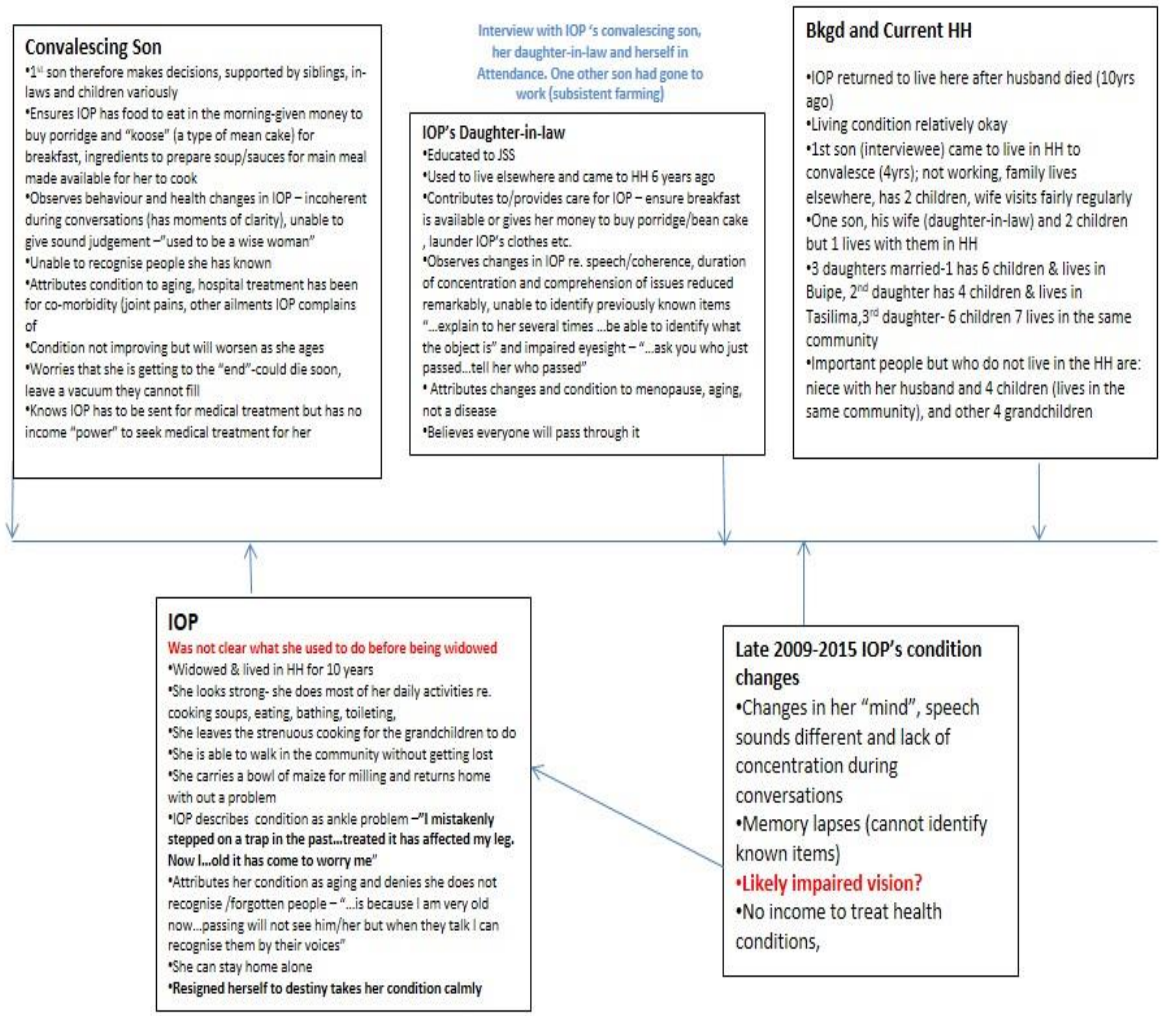
PUNPUANO- RURAL- COMPID – PP 0010 – FEMALE IOP



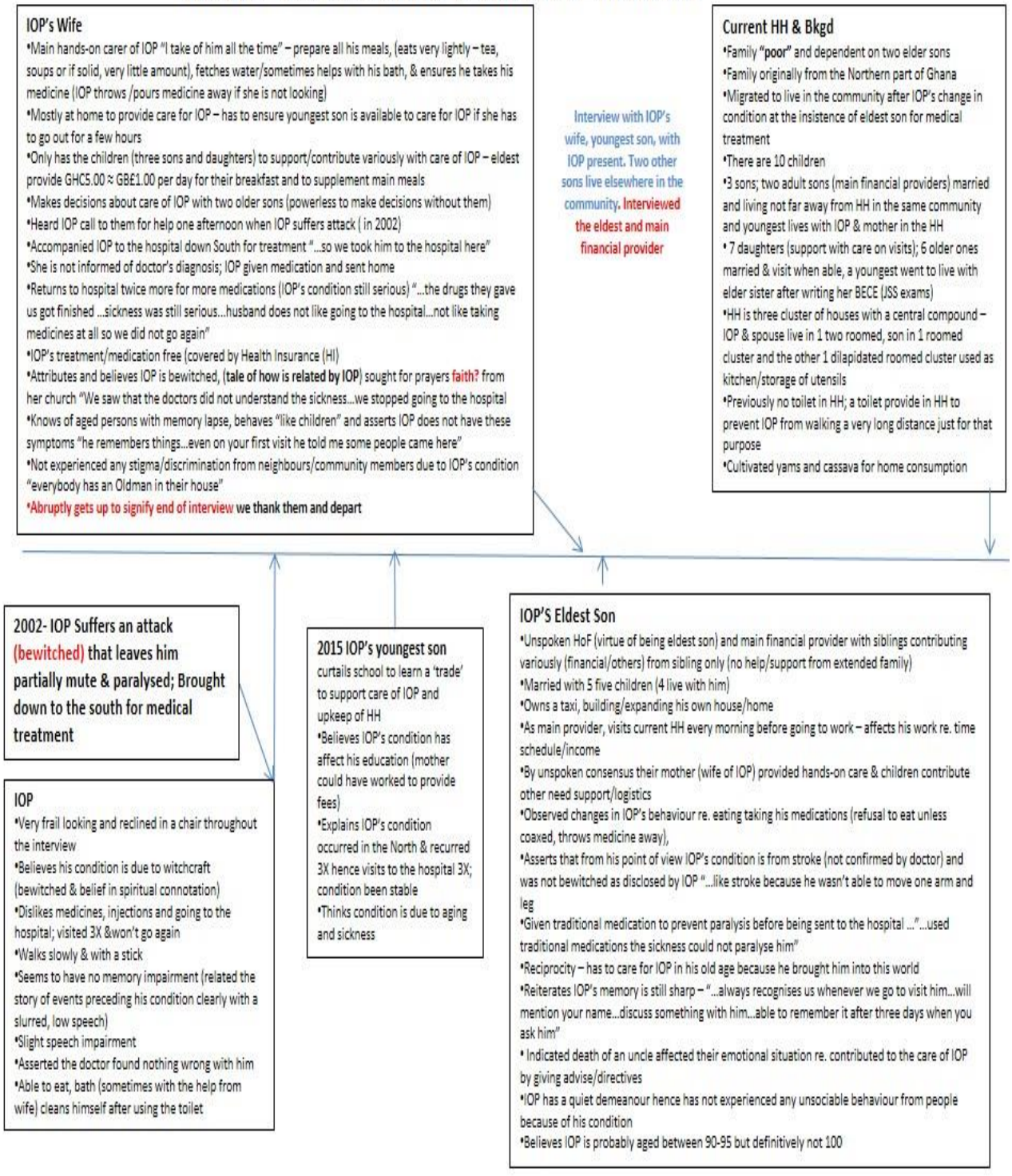
ABODWUM- RURAL- COMPID – AB 0075 – FEMALE IOP



ASANTEKWA – RURAL – COMPID AS 0815 FEMALE IOP



NANTE – RURAL – COMP ID NN 0133 – MALE IOP



BANIANTWE- RURAL- COMPID – BN 0089 – FEMALE IOP

Interview with IOP's daughter
and IOP in attendance